

PILOT TESTING OF A TRANSITION TOOL
FOR RURAL PALLIATIVE CARE PATIENTS
AND THEIR FAMILY CAREGIVERS

A Thesis Submitted to the College of
Graduate Studies and Research
In Partial Fulfillment of the Requirements
For the Degree of Master of Nursing
In the College of Nursing
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ABSTRACT

There is a consensus in the literature that end of life care in rural areas is suboptimal. An intervention transition tool “Changes” was developed for older terminally ill patients and their family caregivers in rural communities to assist them with transitions that cause disruption in their lives. The tool incorporates activities reflecting the critical inputs of awareness, connecting, and redefining normal. "Changes" is an intervention in the form of a binder with an introduction and five sections: 1) Thoughts and Wishes, 2) Common Changes , 3) Resource Section, 4) Travelling Health Record, and 5) Included Resources. The binder utilizes activities to facilitate transitions, relays information on transitions and resources, and answers frequently asked questions. The purpose of this pilot study was to evaluate “Changes” for feasibility, acceptability and ease of use by rural palliative care patients and their family caregivers.

The design for this pilot study was a mixed methods exploratory concurrent design with the quantitative data set providing a supportive secondary role to the qualitative data set. The quantitative data was portrayed through descriptive statistics of an evaluation questionnaire. The qualitative data was collected using an evaluation questionnaire and open ended audio-taped evaluation interviews and analyzed using the interpretive description methodology.

Participants signed a written informed consent and completed a demographic form. Data was collected from eight palliative patients and eight family caregivers from two Western Canadian provinces in Canada. The mean age of the patients was 64.4 years (SD 12.7). Four patients were females and four were males. The length of time the palliative patient participants received palliative care services ranged from one month to 48 months, averaging 12.8 months (SD 17.8). The age of the family caregivers ranged from 55 years to 71 years of age, with a mean age of 65.5 years (SD 6.38). Their relationship to the palliative patient was wives (4), husbands (2), one was a son and another one a friend.

The researcher (in Saskatchewan) as well as a trained research assistant (in Alberta) explained the transition tool to the participants and gave them the tool to look at and work on over a period of one week. The findings of the pilot study evaluation were positive with the majority of participants describing the intervention as acceptable, easy to use and having the

potential to help deal with transitions. Revisions to the intervention tool were made based on the study participants recommendations.

An expanding base of evidence demonstrates that serious deficiencies in quality exist for patients undergoing transitions within palliative care. By studying transitions experienced by palliative patients and their families such as in this study, the nursing care we provide will be based on the knowledge of the dying patient's perspective and that of their family caregiver. This study contributes to the body of nursing knowledge regarding transitions occurring within palliative care and will assist in advocating for improved end of life care by providing evidence based health care. Due to the lack of research to date regarding the use of a transition tool, the findings from this study are unique. The results may in turn facilitate a provision of care by the implementation of "Changes" into nursing practice that will assist individuals approaching death, and those that care for them, in ways that will be meaningful to them.

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DEDICATION

I would like to dedicate this thesis to my parents and my children.

Dad and Mom (P. Lawrence and Margaret Ann Beckie) you have been with me since the beginning. You have supported me throughout my entire life. You have taught me the virtues of faith, hope and love. You have taught me the values of hard work, honesty and integrity. Most of all you have taught me the value of family. I have felt your love and encouragement my entire life and working on this project has been no exception. I love you Mom and Dad!

To Austin, Kelsey, Jory, (Jared R.I.P.), Reid and Justine, my beautiful children, I thank you for being there with me throughout this entire project. I have been supported and cheered on by each one of you in your own ways. Austin and Kelsey, it has been my pleasure to be in university the same time as the both of you and to share your experiences. Jory, my computer guru and go to guy for technical support, the kitchen table will finally be empty of papers. Jared you taught me to value life and enjoy it. Reid and Justine, although you may not have understood exactly what I was doing, you both were very supportive of my work. I hope by my example that all of you will believe in the value of education and that anything is possible. No matter what happens in life, we begin and end with family. I love each and every one of you and am so proud to be your Mom!

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 Introduction

According to the Canadian Nurses Association (2008), there is an abundance of research suggesting a need for improvement in the provision of end of life care in all age groups in Canada. It is projected that by 2036, the number of Canadians 65 years and older will increase from 4.2 million in 2005 to 9.8 million [Canadian Institute for Health Information(CIHI), 2007]. The number of deaths in Canada due to the aging baby-boom cohort could increase by as much as 65% in the same time period (CIHI). With a rising population of older people, who may be coping with multiple comorbid conditions, the demand for palliative care services will rise and become more complex within this age group. For those living in rural and remote areas, the challenges of providing palliative care services is that much more difficult in the rural context (Duggleby et al., 2010). Hospice palliative care aims to relieve suffering and improve the quality of living and dying (Canadian Hospice Palliative Care Association, 2006).

A review of the literature on end of life care for older adults completed by Bolmsjo (2008) emphasized the need to gather more information on people age 65 and older. In particular, she emphasized the importance of exploring the preferences and needs of older adults with regards to end of life care in order to more effectively plan and organize that care. Given the increased demands the baby-boomer cohort will bring, innovative models of end of life care must be evaluated for effectiveness (CIHI, 2007). Along with the demand presented by palliative patients, there will also be a demand placed on the health care system regarding their caregivers. One of the articles that Bolmsjo reviewed uncovered three themes regarding the transition to palliation experienced by the primary caregiver: accepting the patient's impending death, negotiating care for the patient within the health care system and the challenges presented in that negotiation, and the changing roles between patient and caregiver (Schulman-Green et al., 2004). Furthermore, the evaluation of end of life care and the decision-making going into that care may assist the transition from treatment to palliation for all involved (Bolmsjo). Information regarding palliative care needs and expectations from this age group is critical in order to facilitate their care in a way satisfying to these patients and their caregivers during this last phase of their journey.

Transition, a central concept in nursing, has been methodologically analyzed and widely used in the health literature (Kralik, Visentin, & van Loon, 2006). Although a universally acceptable definition of transition has not been developed due to the diversity of contexts in which the term has been used, for the purpose of this pilot study, transitions will be described as ongoing processes characterized by change for an individual (Olsson & Ek, 2002). The conventional use for the term transition has been to demarcate the starting of something new initiated by a change

that people experience (Khalili, 2007) necessitating a shift in the goals of care (Duggleby & Berry, 2005).

As the previously cited review of the literature on end of life care for older adults completed by Bolmsjo (2008) shows, one transition most often centered on in the end of life research literature is the transition from curative to palliative care. This transition requires an acknowledgement by all involved, patients, caregivers, families and health care personnel, that eradication of the underlying disease is no longer possible. Focusing on the control of symptoms and preparation for the end of life are the most important objectives of care with this transition from cure to care.

Similarly, with the increasing recognition that palliative care and end of life care involves complex transitions with considerable change, evidence in the literature to date has also predominantly centered around where and by whom patients are cared for (Lawson, Burge, Critchley & McIntyre, 2006; Back et al., 2008; Duggleby & Berry, 2005). Lawson and colleagues suggest that there is a correlation between patient diagnoses and demographics, and the number of health care transitions occurring. They found that in 3972 patients registered in a comprehensive palliative care program between 1998 and 2002, with 90% having a cancer diagnosis, 47% of the patients make at least one transition during the last month of life. They also found that increased pain and decreased symptom control were significant observations associated with a greater number of transitions. Because the literature has dealt primarily with transitions from cure to care as well as health care transitions, less is known about transitions patients face while receiving palliative care.

Understanding the transitions faced by dying individuals is essential to providing care that is meaningful to them while concurrently relieving suffering and enhancing the quality of the remainder of their lives as they pass through the stages of their illness trajectory. The World Health Organization (2008) defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 1)

Thus, the knowledge gained from studying transitions has the distinct potential to facilitate achievement of the palliative care movement's goals of providing the best possible care; focusing on transitions during palliative care versus to palliative care.

The current guidelines for palliative care are based only to a limited extent on research with dying patients and their families. Heyland et al. (2005) state that decision makers have insufficient information to decide how quality end of life care is defined, how well it is being provided, and whether "current and future policy and clinical interventions will improve the experience of terminally ill patients and their families in Canada" (p. 143). Terry, Olson, Wilss

and Boulton-Lewis (2006) further add that patients often reported divergent perspectives regarding the process of dying from those of their family members. Patients were concerned with privacy and autonomy, primarily regarding their families, lack of information about physical changes and medication, and the desire to shorten life (Terry et al.). On the other hand, they found that family members were predominantly concerned with accessing services and support (Terry et al.). Because patients and their families are often a cohesive dyad moving through the transitions within palliative care, together they constitute an appropriate target for an intervention designed to improve the quality of end of life care. Including both patients and their families participating in interventions, thereby gaining knowledge from both parties, may help to address the needs of all involved in the transitions faced during the palliative phase.

Palliative care services are often limited for palliative patients living in rural and remote settings who wish to remain in their homes or within their own community (Kelley, Habjan & Aegard, 2004). Rural residents and their families within the palliative care service have the additional challenge of reduced access to essential services living in remote areas distant from what have become more specialized, technical, and centralized health care services (McConigley, Kristjanson & Nikoletti, 2001; CIHI, 2006a, 2006b). The influence of living in a rural area and the culture associated with rural living during the palliative experience is essential to understand from both the perspective of the patient and family.

1.2 Relevance and Significance of Study

An expanding base of evidence demonstrates that serious deficiencies in quality exist for patients undergoing transitions within palliative care. These transitions have been recognized as an extremely difficult process for an individual that is fraught with uncertainty and mixed emotions (Burge, Lawson, Critchley & Maxwell, 2005; Lawson et al., 2006; Ronaldson & Devery, 2001; Meier & Beresford, 2008). While a coordinated, palliative care research agenda is slowly evolving, the current reality is that many palliative care researchers have conducted studies on a broad range of topics. The lack of cohesion has resulted in a diffuse array of topics and findings that have actually decreased the collective impact of palliative care research, leading to research gaps in knowledge not presently addressed. Quality research studies in the field of palliative care are being done, but in a sporadic fashion. Consequently, the concept of palliative care is not advanced in a manner that filters down to the patient; end of life care may then be inconsistently implemented for palliative patients. Serious deficiencies in our current knowledge mean that best practices for patients undergoing the palliative approach to care have yet to be developed.

In June 2003, CIHR allotted 16.5 million dollars over five years for palliative care research (Carstairs, 2005). Palliative care research was deemed a priority with this announcement. This priority was a culmination of several factors such as the increase in the aging population, a wide range of palliative care services available to Canadians with lack of consistency in their provision, and an estimated mere 15% of Canadians having access to hospice palliative care

(Carstairs). Standardizing quality end of life care as well as greater access means a need for continued research; its dissemination, and the development and dissemination of best practices.

Studying transitions experienced by palliative patients and their families will increase our knowledge so that nursing practice as care is based on understanding the dying patient's perspective and that of their family caregiver. This increased understanding will assist in supporting the needs and expectations of patients to provide care satisfying to those whom we are entrusted to. Transitions cause dislocation, disorientation, and disruption which can lead to confusion and trauma for patients and their families facing these changes while receiving palliative care (Kralik et al., 2006; Ronaldson & Devery, 2001). Khalili (2007) describes in detail the experience of a palliative care patient diagnosed with a malignant glioblastoma multiforme and his family. As they move through emerging transitions, they describe their journey as a roller coaster ride of uncertainty, fear, and hope. Khalili asserts that the role of the nurse becomes one of recognizing the needs of the patient and family at each point of transition, and helping them cope with the multiple losses and constant adjustments induced by the transitions. Facilitating transitions is widely acknowledged as being a central concept for nursing (Schumacher & Meleis, 1994). Thus, increasing our knowledge of transitions within palliative care is imperative to aid this major role for nurses and improve the quality of life for those we serve.

1.3 Research Purpose and Specific Aims

The paucity of research available regarding rural older palliative care patients and their family caregivers creates a gap, an urgency that is made more critical because of factors such as the aging population, extended longevity, and inaccessibility to palliative care for the rural population. With the proliferation of aging seniors, the mélange of services available to rural Canadians, the increasing recognition that palliative care and end of life care involves complex transitions: transitions within palliative care warrants attention. A concentration on an older, rural demographic is crucial for narrowing the gap of potentially vast inequalities in the quality of care for both palliative care patients and their family caregivers within this population.

Based on the findings of a qualitative study (Duggleby et al., 2010) and an expert panel Delphi study, a transition tool entitled "Changes" was developed (Appendix A). "Changes" is an intervention tool developed to facilitate improvement in the lives of older rural palliative patients and their families. The tool incorporates activities reflecting the critical inputs of awareness, connecting, and redefining normal as delineated in the qualitative study undertaken by Duggleby and colleagues. "Changes" is an intervention in the form of a binder with an introduction and five sections: 1) Thoughts and Wishes, 2) Common Changes, 3) Resource Section, 4) Travelling Health Record, and 5) Included Resources. The binder utilizes activities to facilitate transitions, relays information on transitions and resources, and answers frequently asked questions. "Changes" was designed to help older rural palliative care patients and their family

caregivers prepare for possible changes or events and to connect these people with services in the community that may be of benefit to them as they experience transitions.

Little is known about the effectiveness of interventions in fostering a more collaborative role between palliative care patients, their caregivers and their health care providers to champion a more improved quality of life facing transitions during the palliative phase of their lives. The purpose of this pilot study was to evaluate the “Changes” transition tool for ease of use, feasibility, and acceptability for palliative care patients and their family caregivers in rural communities. The specific aims of this study were to: a) evaluate the study procedures to determine if they are realistic and workable, b) evaluate the tool for ease of use, acceptability, and feasibility for rural palliative patients and their family caregivers, and c) collect preliminary data to determine the potential effectiveness of the tool for increasing quality of life and hope scores of patients and caregivers.

This study contributes to the body of nursing knowledge regarding transitions occurring within palliative care and advocates for improved end of life care by providing evidence based health care. Due to the lack of research to date regarding the use of a transition tool to assist palliative care patients and their family caregivers with transitions occurring within palliative care, this study using a mixed methods approach incorporating both quantitative data and qualitative data may be helpful in evaluating the “Changes” transition tool more thoroughly than just utilizing one form of data. The tool may in turn facilitate a provision of care that will assist individuals approaching death, and those that care for them, in ways that will be meaningful to them by greatly enhancing their quality of life and hope. Research resulting in an evidence-based “Changes” transition tool may ease suffering and increase quality of life for patients and their family caregivers as they have the benefit of its use for the remainder of their time in this life together. Palliative patients and their family caregivers each have a place of their own in this binder to record their private thoughts and have as a resource throughout their time in palliative care. “I am a traveller on the journey from one life to the next, and I need a place where I can be welcomed and looked after and cared for and be myself on that journey” (Hospice Palliative Care Association of Prince Edward Island, n.d., p. 1).

CHAPTER TWO: REVIEW OF THE LITERATURE

A broad literature search was conducted using CINAHL, ProQuest, Scopus, Medline and Google Scholar capturing relevant research literature from 2000-2010 examining adult palliative care. The search terms used were palliative care, end of life care and terminal care within the confines of adult individuals and articles written in English. This literature search, conducted electronically and by hand, discovered most of the literature pertaining to the many facets of the palliative care experience originates in the United Kingdom, Europe, and the United States. Clearly, caution is needed when interpreting the results from the Canadian context.

The following review of the literature is broken down into four main parts drawn from the areas of concern regarding this pilot study. The conceptual framework guiding the study, the rural aspect of palliative care, the aging population and palliative care, and transitions in general and more specifically in palliative care will be reviewed and synthesized. Finally, the state of the science as well as gaps in knowledge regarding transitions for rural older palliative care patients and their families will be discussed briefly.

2.1 Conceptual Framework

The concept of transition, although utilized across social science and health disciplines, has been systematically analyzed with regards to the discipline of nursing. Two theories have been articulated to guide nursing research and theory development (Selder, 1989; Meleis et al., 2000). Selder developed a life transition theory, while Meleis and colleagues outlined a middle-range theory to be utilized by the nursing profession.

Selder (1989) developed a life transition theory that involves the process of restructuring reality and resolving uncertainty. She highlights the importance of a person's need to acknowledge that a prior way of existing has ended, or a current reality is under threat, and that change needs to occur before the transition process can begin. With this acknowledgement accomplished, it is then possible to make sense of what is happening and reorganize a new way to live, respond, and be in the world. Selder argues that uncertainty motivates this restructuring of reality or transition process that includes confronting circumstances, acknowledgement, information-seeking behaviour, and transition strategies. It is further maintained that the goal for each person experiencing a transition is to maintain their sense of self throughout the process (Selder).

Meleis, Sawyer, Im, Hilfinger Messias and Schumacher (2010) outlined a middle-range theory of transitions that suggests that the patterns of transition (single, multiple, sequential, or simultaneous) are important considerations while determining the types of transitions (health/illness, situational). According to Meleis et al., when a person is feeling connected to and interacting with their situation and other people, they feel able to reflect and interact, developing increasing confidence in coping with change and developing mastery of new skills to cope with life while developing a more flexible sense of identity in the process. They suggest

that successful transitions result from patients feeling connected, having a sense of mastery, and are effectively coping to develop an integrated identity. Additional properties of importance when considering transitions include individuals noticing what has changed and how things are different, time span, and critical points and events. For example, to be in transition requires an awareness that the changes are occurring and engagement with these changes means seeking information or support, identifying new strategies for living and being, modifying previous strategies, and making sense of the present circumstances (Meleis et al.). Finally, the theory proposes personal and environmental facilitators and inhibitors of healthy transitions that include meaning, cultural beliefs, socioeconomic status, preparation and knowledge, and community and societal beliefs.

Gaps exist in both of these theories related to the relational nature of transitions and the importance of maintaining personhood with regards to palliative patients and their families (Duggleby et al., 2010). The life transition theory proposed by Selzer (1989) describes how individuals restructure their reality and resolve uncertainty. Furthermore, she states that the shape of the transition is the resolution of the uncertainty. This theory is not applicable to palliative care as it is very individualistic. The basic unit of care within palliative care is not only the patient, but the family as well. Additionally palliative care patients are often dealing with multiple simultaneously occurring uncertainties facing an uncertain future, not just one uncertainty. Regarding the transition theory that Meleis and colleagues (2010) propose, this theory too is not applicable to the palliative care population. While this transition theory does acknowledge the patterns of transitions (single, multiple, sequential, or simultaneous) as an important consideration, it is again very individualistic. Again, palliative care is concerned not only about the patient, but their family as well making this theory not applicable in this set of circumstances.

A recent grounded theory study describes the transition processes of rural palliative care patients and their family caregivers (Duggleby et al.). The purpose of this study was to explore the transition experience and the associated processes of rural older palliative patients and their families. Palliative care patients, bereaved family caregivers, and rural palliative care providers were interviewed. Twenty eight participants described their experiences in dealing with transitions. Specifically, they experienced multiple transitions within the framework of rural isolation, lack of information, decreased access to services, placing value on individuality and the closeness of community ties (Duggleby et al.). Duggleby and colleagues found that the transitions of palliative patients and their families were undertaken by coming to terms with their situation, an awareness of the change in their situation, connecting by seeking information, searching for options and requesting help from trusted experts, and redefining normal through communication and the information garnered from experts all through the process of navigating unknown waters and thus restructuring their reality (see Figure 1). Therefore, rural palliative patients and their families managed transitions through the process of navigating unknown waters with the assistance of timely communication, information, and support networks. While

established theories (Selder, 1989; Meleis et al., 2010) add to the body of knowledge surrounding transitions, Duggleby et al.'s theory in relation to transitions provides a useful framework within which to interpret the research literature to provide more specific guidelines for palliative care nursing practice, and to derive clear research questions and relevant outcomes for assessment. This theory will require testing as it builds on previous transition theories with the added credibility of having palliative care patients, bereaved family caregivers and palliative care providers lend their voices to its foundation.

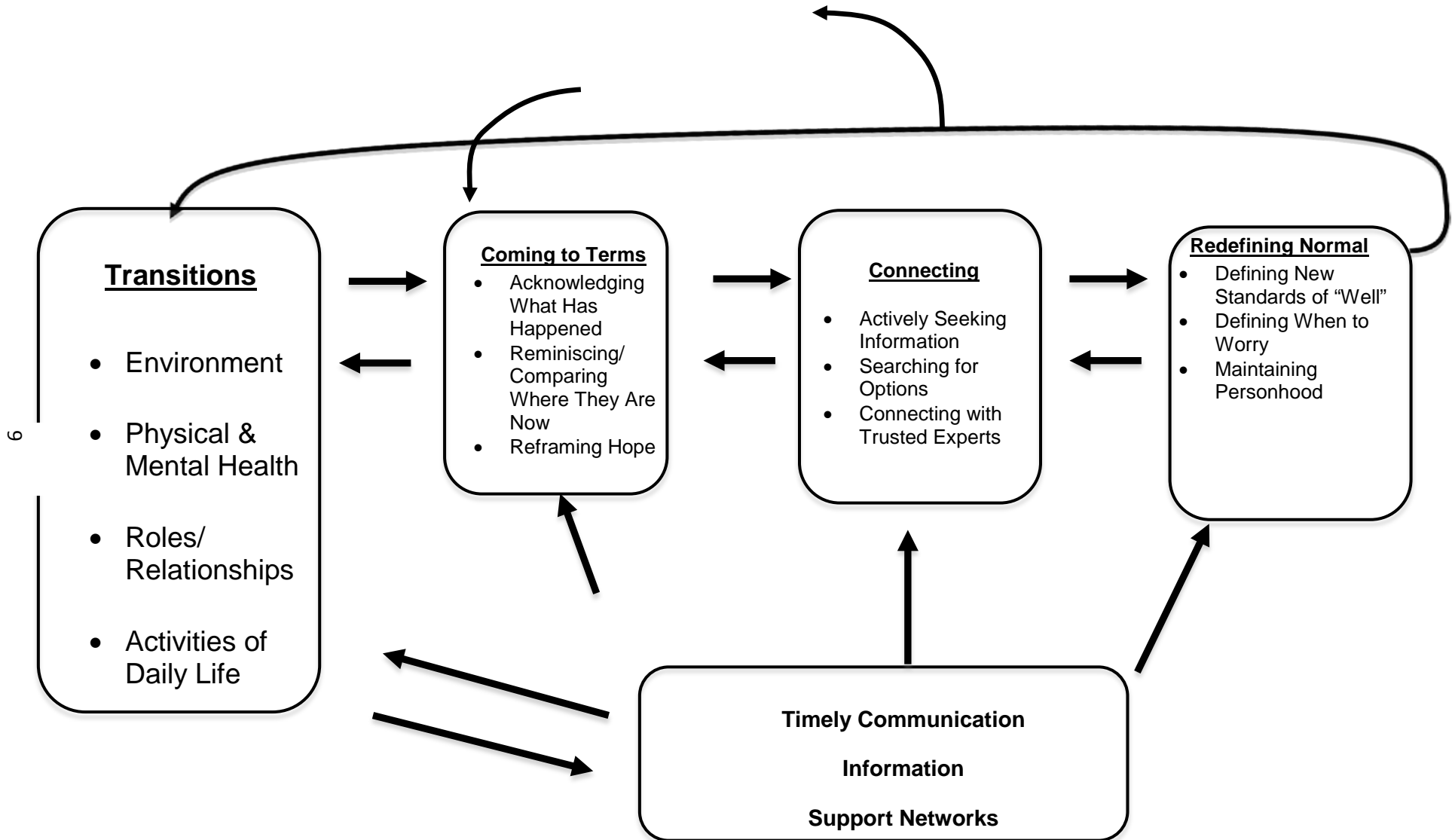


Figure 1: Navigating Unknown Waters (Duggleby et al., 2010, p.6)

2.2 Rural Aspect of Palliative Care

In addition to the broad literature search conducted regarding adult palliative care, a literature search was conducted specifically for the rural aspect of palliative care. The search encompassing the MEDLINE, CINAHL, ProQuest and SCOPUS databases was conducted from literature published between 2000 and 2010 utilizing the search terms rural, remote, palliative care, terminal care, and end of life care. The references of the retrieved articles were also hand searched for further relevant articles. The literature search produced four systematic literature reviews, one summary report, 12 studies and one editorial pertaining to such topics as rural health research in general, where a patient dies, healthcare transfers at the end of life, barriers to quality care, rural palliative care models, palliative care education programs for professional providers as well as innovative delivery of health care services in the rural areas.

In June 2000, the CIHR was formed and all health researchers, including rural health researchers, were encouraged to critique their areas of research and to plan future directions (Pong, 2000). Research on palliative care for rural populations was in its infancy. The paucity of published research revealed sparse services and a huge window of opportunity to improve rural palliative care services for terminally ill patients. As a result, the unique nature of palliative care provision in rural communities was not being addressed adequately.

Evans, Stone, and Elwyn (2003) conducted the first systematic literature review in the field of rural palliative care. They found little published work (26 studies) between 1991 and 2001 that examined the organization of rural palliative care and the views of professionals providing this care in rural areas. The vast majority of studies published prior to 2000 originated in Australia, which could lead to the belief that greater investment in rural palliative care research was occurring in Australia versus any other continent at that time. The studies (10 surveys, three qualitative studies and 13 reports) reviewed unveiled a weak literature base that prevented making any definitive conclusions on the most effective organization of palliative care in rural areas. A recurring theme throughout the articles reviewed was the importance of primary care professionals, such as general practitioners and home care nurses, to the delivery of palliative care services in rural areas. However, problems of primary health care professionals, families and carers feeling overwhelmed and unsupported were identified in rural palliative care delivery. Evans et al. concluded that there was a need to further research the best way to organize, support and expand the delivery of palliative care.

Hughes, Ingleton, Noble, and Clark (2004) completed a broad review of the rural palliative care literature encompassing the years 1985-2000 focusing on the needs of patients and caregivers. Of the twenty papers reviewed, four had been previously reviewed by Evans et al. (2003). The majority (11) of the twenty papers reviewed specifically examined the needs of patients and caregivers. Five papers were surveys of place of death or end of life care and four papers were reviews of palliative care services provided including sections on the needs of patients and caregivers. Across the wide range of methodologies (surveys, focus groups,

interviews: both semi-structured and in-depth structured) an underlying theme that palliative care services provided to rural residents needed to be improved prevailed among the participants. Issues identified specific to rural residents receiving palliative care were geographical distance necessitating potentially long commutes to access specialist care and treatment, the need for information, the importance of informal networks in providing care, and the burden that informal carers may experience in providing care due to lack of sufficient local provision of formal professional support.

Wilson et al. (2006) conducted a systematic literature review on rural end of life care from 1988-2003 to determine the issues specific to rural end of life care in order to plan and provide that care. Thirty six articles, mostly small studies focusing on one rural region or a small percentage of total rural regions in the area, were identified with over half having a quantitative (one randomized controlled trial, the remainder exploratory or descriptive comparative) design followed by studies with qualitative designs, and finally 2 mixed methods studies, with interviews being a common method of data collection. The articles reviewed dealt with exploring the differences between urban and rural end of life care, examining rural end of life care, ascertaining rural end of life care needs and wishes, and uncovering the need for continuing end of life health care education for rural providers. One commonality among the studies is that rural communities are unique and their end of life care involves different needs and wishes than their urban end of life counterparts. Furthermore, end of life care, whether hospital based or home care, needs to be integrated into any rural health care organization, because, dying patients and their family caregivers want to remain in their rural homes or home community. As well, family caregivers need information and support as rural patients have limited access to specialized palliative care. Lastly they conclude that rural care providers, and one could infer their clients, would receive great benefit being supported by palliative care specialists in both continuing education and general moral support in a common goal of providing palliative care (Wilson et al.).

Following this third systematic review, an editorial appeared in the Society of Rural Physicians (Crooks & Schuurman, 2008) urging the palliative care movement to create models of rural palliative care to meet the unique needs of this population. Additionally, it is clearly stated in this editorial that these models need to be developed before the service becomes overwhelmed by the aging population and the subsequent increase in the demand for palliative care services. Furthermore, there is a developing trend of people relocating to rural areas upon retirement that may lead to undue stress on rural palliative care providers, especially if models or frameworks are not in place guiding their care. Consequently, the quality of care given to palliative care patients and their families may be compromised if this population's service needs are not addressed now, before the demand rises.

As shown in the previous three reviews, palliative patients living in rural and remote settings have limited access to integrated palliative care. With the primary purpose of developing a research mandate to inform policy and program development in rural areas, a comprehensive

review of rural palliative care research was undertaken by Robinson et al. (2009). They found the body of rural palliative care research small and variable in both topics and approaches providing a weak base of support for informing palliative care policy and development of services in the rural setting. They concentrated on studies between 1996 and 2007 with a total of 79 studies reviewed. Twenty-four studies assessed patient and caregiver perspectives of palliative care, rural health care provider's perspectives were the focus of twenty-eight studies, and twenty-seven articles dealt with various aspects of rural health care delivery services. Robinson et al. emphasize that the diverseness in both topics and research methods in the area of rural palliative care is detrimental to developing a body of knowledge to support effective policy and program development. They extend this by stating that a coordinated program of research is needed and that a strong theoretical basis may provide a way to align research efforts. With regards to the literature on health care services, they add that there is a need for "Innovative models of service provision and the rigorous evaluation of these models in order to effectively address the unique aspects of palliative care in rural and remote settings" (Robinson et al., 2009) p. 256.

Wilson et al. (2009) report rural people's perspective on a good death in their ethnographic study (13 individual interviews, 2 focus groups totalling 21 participants). The most important belief they uncovered from the rural people interviewed for this study was that dying persons should be cared for and die in their home community. Also, the belief that palliative care must allow a person to die with dignity was prevalent. Other major points discovered were that gaps in service throughout rural areas are widespread, formal services by health care providers are augmented by informal services in the community such as church groups, and that providers need to be current in their palliative care knowledge as well as increase awareness of the resources available. Emphasis was also placed on the importance for health care providers to be sensitive to the high value rural communities place on dying well which can only be supported by high quality palliative care.

Research on rural palliative care has tended to focus on identifying problems rather than providing evidence to support effective interventions. Of the two Canadian studies retrieved addressing the effect of rural residency on where a patient dies, one study conducted in Nova Scotia (Burge, Lawson, & Johnston, 2005) examined 13,652 cancer deaths from 1992 to 1997 using secondary data analysis of administrative health data. They found that rural cancer patients were more likely to die in hospital than their urban counterparts. A second study conducted in Manitoba (Menec, Nowicki, & Kalischuk, 2010) examined administrative health care records of all adults who died in that province in 2003-2004. They found that residents of four out of the seven rural/remote regions in the province had higher odds of being hospitalized at the end of life, relative to urban residents. The authors warn that over- generalization of the findings should not be made without considering the local differences in health care resources. Even though the general flavour of the research literature on place of death reveals that patients

wish to die at home and not in hospital (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005) these two studies reveal that most rural palliative care patients die in hospital.

Van Vorst et al. (2006) examined rural health care provider's perceptions of care given to rural palliative patients in rural Kansas and rural Colorado. The 363 respondents of the completed surveys cited family members' avoidance of issues around dying, differing opinions among health care providers, and patients' avoidance of issues around dying as the three most common barriers to providing the best possible end of life care. Similarly, a survey completed by Mathews, West, and Buehler (2009) found that there was no link between cost considerations of various treatment options and the patient's actual cancer treatment decisions. However, they found that rural patients do take into account these costs when deciding on treatment options disproportionately to their urban counterparts. Of the 484 adult cancer clinic patients surveyed from cancer clinics in Newfoundland and Labrador between September 2002 and June 2003, 46% were considered rural. Rural residents were slightly more than twice as likely as urban residents to report that financial costs (travel costs 1.79x, childcare 2.33x, and costs of drugs 1.69x) were important considerations in their care decisions after starting treatment. The findings of both surveys suggest rural residents may have decreased access due to the barriers aforementioned.

Even though rural palliative care research has tended to focus on identifying areas of concern rather than providing evidence to support effective interventions, there have been studies performed emphasizing the positive developments happening in the world of rural palliative care services. As the demand for palliative care services rises due to the aging population and awareness of decreased access and lack of resources is being made known including inconsistent provision of services, innovative ways of developing the delivery of palliative care services are being studied. Kelley (2007) utilizing the theory of community capacity development shows how rural communities develop palliative care programs and how this knowledge can be translated to other rural communities not as fully developed in the area of palliative care. Kortes-Miller, Habjan, Kelley, and Fortier (2007) states that the 85 plus age group is the fastest growing cohort in Canada with long term care homes increasingly becoming a common alternative to end of life care, especially in rural areas with decreased services. With this increase demand there is a pressing need for staff to have the necessary education to provide palliative care. They describe the development and delivery of a palliative care education program in rural long term care facilities. Emphasizing this knowledge translation from research to implementing education and palliative care delivery models is a positive step forward in providing rural palliative care.

Additional evidence to support effective interventions in palliative care delivery was provided by two evaluations of local pilot projects in Australia and two in Canada. Broadbent and McKenzie (2006) examined the development of a visiting palliative medicine specialist outreach service in rural Australia. They discuss the benefits of the service, especially the

reduction in the symptom burden, providing evidence of its need, but state further research is required to study the service more comprehensively. A second study published in 2006 by Eager, Owen, Masso and Quinsey used participant observation as well as a survey to describe the impact of a new palliative care model developed for patients, caregivers and staff in rural Australia. The model includes a foundation of procedures such as the use of common referral criteria for palliative care services, weekly case conference meetings between healthcare disciplines, an on-call nursing roster to provide access to services at all times as well as the creation of a patient-held record to name a few. There was a noticeable improvement to service delivery shown by decreased fragmentation of service and variable after-hours coverage by improved coordination of services, as well as enhanced support and work relations across professional disciplines using a multidisciplinary approach.

In rural Alberta the use of a combination of conventional and home telehealth video visits versus conventional palliative home care visits regarding symptom management and quality of life for rural palliative home care patients was evaluated and it was found that further research is needed to determine if telehealth video visits have enough value to make the changes necessary for implementation (Hebert, Brant, Hailey, & van der Pol, 2006). In 2009, palliative care services utilization in semi-rural British Columbia was assessed with the intention of informing program and policy decisions (Allan, Waskiewich, Stajdubar & Bidgood, 2009). The authors determined that the information was limited as the perspective of patients or family members was not sought. Thus the ability to assess if the local resident's needs were met could not be addressed. Hence, there is evidence to show that palliative care research with regards to rural areas is on the radar and gaining attention on the worldwide stage.

Although, these studies provide windows of knowledge into the general topic of rural palliative care, it is at first glance an uncoordinated, incoherent and unfocused movement of research. Throughout the past ten years, the research has uncovered problems rural patients and their caregivers face with access to palliative care services, as well as their preferences in what they do and do not want out of palliative care services. However, the body of research at present is providing minimal evidence on what palliative care services are available and how well they are working for patients and their families. The most significant gap in the literature according to Robinson et al. (2009) is the missing perspective of palliative patients and their families regarding their experiences within rural and remote settings.

Developing, expanding and evaluating effective health care services at the end of life for both rural palliative patients and their families is a pressing need to guide palliative care provision in rural and remote areas. Rural Canadians are at higher risk for ill health and unmet healthcare needs living far from highly specialized and centralized health care services (CIHI, 2006a, 2006b). With rural Canadians numbering greater than 30 percent of the population (Government of Canada, 2002) and estimates of only 15 percent of all Canadians having access to palliative care services (Carstairs, 2005), there is a substantial need for developing and

evaluating effective health care services. The need is considerably greater for rural palliative patients who are faced with the additional challenges of reduced and difficult access to needed services which are often found only in distant larger centers.

2.3 Aging Population and Palliative Care

A literature search encompassing 2000-2010 was conducted to assess the state of literature specifically regarding older adults using MEDLINE, CINAHL, ProQuest and SCOPUS databases. The search focused on adults 65 years and older, end of life care, terminal care and palliative care. The references of the retrieved articles were also hand searched for further relevant articles. The search produced one CIHI report on western Canadian end of life health care and one Senate of Canada progress report on quality end of life care, one literature review, and studies on improving both the provision of care to older adults and enhancing access as well as identifying end of life treatment preferences for older adults. There is an abundance of literature with regards to the general search terms of end of life care, terminal care and palliative care. As the search term elderly or older adults is added in to the literature search parameters, the number of studies listed drops dramatically especially when studies dealing with family caregivers and not the palliative patient, specific diseases, and prolongation of life as the focus are excluded for the purpose of this literature review.

Demographic changes are leading to an increase in the number of older people who have long-term and life-limiting illnesses. As Canadian baby boomers age and the older population increases, unprecedented numbers of older adults are living longer often with chronic diseases. More dependence on the health care system with an increasing need for end of life care has resulted. As the population ages and the demand for all health care services rises, the palliative care movement will need to be prepared for the corresponding rise in the demand for their services. It is estimated that 8 million Canadians, or approximately 20% of the population, will be over the age of 65 by 2026 (Carstairs, 2005). According to Statistics Canada (2006), seniors 65 and older are projected to increase to 9.8 million by 2036 increasing their share of the population to 25%. With an aging population, the need for palliative care increases accordingly. An integrated systematic approach to palliative care services with improved access and a coordinated approach to quality end of life care is required.

Bolmsjo (2008) conducted a review of the literature between 1990 and 2007 on end of life care for older people. She states that more knowledge of end of life care for people age 65 and older is needed to plan and organize care. Using the inclusion criteria of studies dealing with people 65 years and older, studies making reference to end of life care interventions, and studies with adequate scientific strength with respect to validity, reliability and critical discussion, 29 studies, most originating in the United States, were evaluated for this review. The studies were then grouped into four headings of education and support for close relatives, education and support for staff, education and support for patients, and care planning articles. One of the four

key findings in this review is that access to palliative care is very dependent on the services available, if there are any at all. Furthermore, access to palliative care for everyone who suffers from a life-limiting illness, including the very old, should be a goal the palliative care movement strives for (Bolmsjo). Consequently, Bolmsjo states that further research is needed with regard to issues of access. Secondly, the topics of concern regarding family members and informal caregivers were feeling responsible for the patient, wanting professional support, abusive family relationships, and uncertainty in their ability to provide care. Overall, it was emphasized that family members play an essential role in the care of dying patients. Another finding was that many of the interventions studied focus on team work and care planning with the aim of improving end of life care. Lastly, Bolmsjo concludes that the results of the majority of palliative care studies are limited due to methodological weaknesses inhibiting generalizations of the findings. She asserts that questions remain to be answered as the palliative population is not conducive to being tested by large randomized controlled studies. The scientific gaps in palliative care research that she would like filled in are concerning geographical and cultural areas other than the United States, the end of life care needs and wishes of older adults and the effect of palliative care models .

Nahm and Resnick's (2001) descriptive study of 191 participants found that many older adults preferred comforting measures rather than aggressive interventions at the end of life. Lee, Coakley, Dahlin and Carleton (2009) echo this finding stating that the needs and preferences of older adults are not always addressed by technological advances and the increasing complexity of health care. An additional finding of Nahm and Resnick (2001) was that treatment choices may change over time and across illness progression necessitating re-evaluation at regular intervals. Providing optimal end of life care to older adults will require continued research and dissemination addressing health care preferences and quality end of life care for older adults.

As the population ages and the demand for all health care services rises, the palliative care movement will need to be prepared for the corresponding rise in the demand for their services. There is an urgent need to develop innovative, integrated, and systematic approaches to palliative care for this demographic. Further research is required in this area to expand the knowledge of older adults and their preferences for care. It must be ensured that carers are included in this research as they have been found to be an invaluable component to care provision.

2.4 Transitions

Transitions are particularly critical to study as there is evidence that the processes could be managed effectively by assisting health care professionals to develop appropriate delivery of palliative care (Ronaldson & Devery, 2001). Examples of transitions experienced by palliative patients and their families include changes in roles, relationships, loss, care settings, goals of care, hope, meaning and purpose in life, physical and mental health, and independence (Khalili, 2007; Schumacher & Meleis, 1994; Duggleby & Berry, 2005). Complicated by the fears surrounding impending death, constrained by a lack of time to prepare patients and their families,

and insufficient information given to the patients and caregivers, transitions can lead to less than a gold standard quality of care for palliative patients and their families (Marsella, 2009).

Both patient-oriented (biopsychosocial deficits) and system-oriented factors (communication breakdown between providers and agencies, insufficient patient and caregiver education, poor continuity of care, and limited health access) jeopardize successful transitions (Naylor, 2003). Factors contributing to making any transitions during this vulnerable time period of palliation less than favourable include multiple health care practitioners and multiple prescribers (Meier & Beresford, 2008), poor communication between patients, families and care providers (Grunfeld, Folkes, & Urquhart, 2008), and suboptimal access to care (Robinson et al., 2009). These unfavourable factors leads to patients having unmet needs (Fitzsimons et al., 2007), dissatisfaction (Heyland et al., 2005), poor quality end of life care (Barbera et al., 2006), increased hospitalizations (Neutal, Bishop, Harper & Gaudette, 2005), medication errors (Meier & Beresford, 2008), and increased health care costs particularly at the end of life (Brumley et al., 2007). Supporting people through transitions falls under the realm of health care professionals, especially nurses, whom care for many people undergoing transitions. Health care personnel using effective strategies developed for the delivery of palliative care during this vulnerable time of transition can lead to a better quality of life.

While there is a body of research surrounding the topic of transitions in palliative care, the predominant focus is on two main areas. The first area is the transition of patients from curative to palliative care and the second on health system transitions centering on where and by whom the patient is cared for. Therefore, the experience felt by palliative patients and their caregivers of the transitions they undergo within palliative care is overlooked by this type of research. Focusing research efforts on the location of where palliative patients are cared for and which clinical service provides care to the palliative patient is justifiable. However, closer examination is required to understand these transitions so that care can be designed or modified to address the experience of patients and their family caregivers as they navigate through transitions (Burge et al., 2005). Duggleby and Berry (2005) describing four case studies found that oncology nurses could support palliative patients and their families undergoing transitions. By understanding where patients are at in the process of adjusting to death, accepting them at this place, and supporting patients as they shift their goals of care when experiencing transitions, oncology nurses are able to fulfill their role in facilitating these transitions (Duggleby & Berry). Larkin, Dierckx de Casterlé, and Schotsman (2007), using a phenomenological approach in a qualitative study, asked 120 palliative care patients from six European countries to describe their transition experience towards the end of life. The overarching theme describing the study participant's experience was "living transiently in the shadow of death" (p. 73). At the time of their research, the authors suggested that transition as then described in the literature warranted further study to be clearly understood in the palliative population. Thus, the concept of transition needs to be operationalized with a clear definition in order to advance the study of this concept.

Transitions are a part of everyone's life. We all experience change as change is inevitable. As health care professionals entrusted to caring for patients who know their death is imminent, it is our duty to assist our patients through transitions. We will only be able to accomplish this by researching transitions as palliative patients and their carers move through them, forging new and effective ways in dealing with them as guided by their need.

2.5 State of Science and Gaps in Knowledge

The area of palliative care research is fraught with problems due to the vulnerability of the population being studied. There are of course other obvious factors detrimental to conducting this type of research. The factors include, but are not limited to, the difficulties of recruitment and the fact that death and dying brings out the strongest emotions in people, some of whom wish to remain private, and high rates of attrition. Motivating people to continue to be study participants even when they progress in their illness trajectory and by working compassionately with patients and caregivers may be a way to move forward (Thomas, Wilson & Sheps, 2006) in the research process of this population.

Within the context of rurality and older adults, the effectiveness of palliative care interventions which may provide clinically relevant and meaningful outcomes for the palliative population is essential to study. Further study is necessary to examine transitions and testing of the Navigating Unknown Waters Theory (Duggleby et al., 2010) to provide comprehensive research in this area to evaluate generalizable palliative care interventions. Palliative care research to date has not focused on intervention tools to facilitate the palliative care experience especially with regards to transitions within palliative care. There is a need to focus on transitions from cure to care, but equally important is the transitions within palliative care. Additionally, research regarding rural aspects of palliative care shows a need for improved services which in some parts of the country are very sparse which may lead to unmet needs. A transition tool such as "Changes" could help to fill those needs. Research incorporating palliative patients and their family caregivers is essential to meeting those needs with regards to any intervention tool.

CHAPTER THREE: METHODOLOGY

The overall purpose of this study was to pilot test a transition tool called “Changes” for ease of use, feasibility and acceptability. It was developed, based on the findings of a qualitative study (Duggleby et al., 2010) and an expert panel Delphi study, for older terminally ill patients and their families in rural communities to assist them with transitions. The tool incorporates activities reflecting the critical inputs of awareness, connecting, and redefining normal as delineated in the qualitative study undertaken by Duggleby and colleagues. “Changes” is an intervention in the form of a binder with an introduction and five sections: 1) Thoughts and Wishes, 2) Common Changes, 3) Resource Section, 4) Travelling Health Record, and 5) Included Resources. The binder utilizes activities to facilitate transitions, relays information on transitions and resources, and answers frequently asked questions. The specific aims of the pilot study were to: a) evaluate the study procedures to determine if they are realistic and workable, b) evaluate the tool for ease of use, acceptability, and feasibility for rural palliative patients and their family caregivers, and c) collect preliminary data to determine the potential effectiveness of the tool for increasing quality of life and hope scores of patients and family caregivers.

3.1 Research Design

The research design for this pilot study was conducted using a mixed methods exploratory concurrent design (QUAL-quan) in which a quantitative data set provides a supportive, secondary role to the qualitative data set. The design, with the emphasis on the qualitative data, was in alignment to best address the study’s purpose of evaluating the “Changes” tool. It was the intent that the potential strength and quality of the data provided by predominantly collecting qualitative data from study participants would generate understanding regarding the use of the tool. This knowledge would shape the product of evidence to put the “Changes” tool into practice. Arain, Campbell, Cooper and Lancaster (2010) state that while pilot studies may not produce statistically significant results, well conducted pilot studies are important for research. Furthermore, they state that the prevalence of pilot studies may be expected to increase in the evaluation of multifaceted interventions.

This pilot used a concurrent embedded approach with qualitative and quantitative data collected at the same time. Creswell and Plano Clark (2007) state that this type of mixed methods design is based on the assertion that different questions need to be answered by different types of data and that a single data set is not sufficient. They further argue that data collected concurrently may be analyzed with the intention to validate one form of data through the other form (Creswell & Plano Clark). In the case of this pilot study, the quantitative data set will be analyzed and used to validate the qualitative data set with regards to the evaluation of the “Changes” tool.

The methodology of interpretive description was chosen and applied to the qualitative research design of this pilot study to address the study purpose and aims (Thorne, Reimer

Kirkham & MacDonald-Emes, 1997; Thorne, Reimer Kirkham & O'Flynn-Magee, 2004; Thorne, 2008). Historically, qualitative research methods have centered on the utilization of phenomenology from the discipline of philosophy, grounded social theory from the discipline of sociology and ethnography from the discipline of cultural anthropology (Thorne et al., 1997). Within the confines of these three methodologies, questions from the field of nursing regarding health and illness experiences using these qualitative research methodologies remained to be fully answered. An approach was required to gain a better understanding of complex phenomena experienced by patients to gain new insights to shape applications of evidence to practice (Thorne). Thorne further argues that new knowledge is essential in the realm of “subjective, experiential, tacit, and patterned aspects of human health experience” (Thorne, 2008, p. 36) so as to guide future clinical decisions applying real evidence to real people instead of solely advancing theory development.

Interpretive description gives common elements to phenomena, as well as individualism and in doing so enables the information gathered to be interpreted for a clinical understanding leading to application (Thorne, 2008). In this pilot study, data collected both qualitatively and quantitatively led to grouping both common elements of the experience of using the binder and being a participant in the study, as well as individualized elements unique to each participant's experience with using the binder and being a study participant. Thus, the individual experience of each participant contributes to the overall evaluation of the process of using the “Changes” intervention collectively.

The data collection plan for the study, both of a quantitative and qualitative nature can be found in Figure 2.

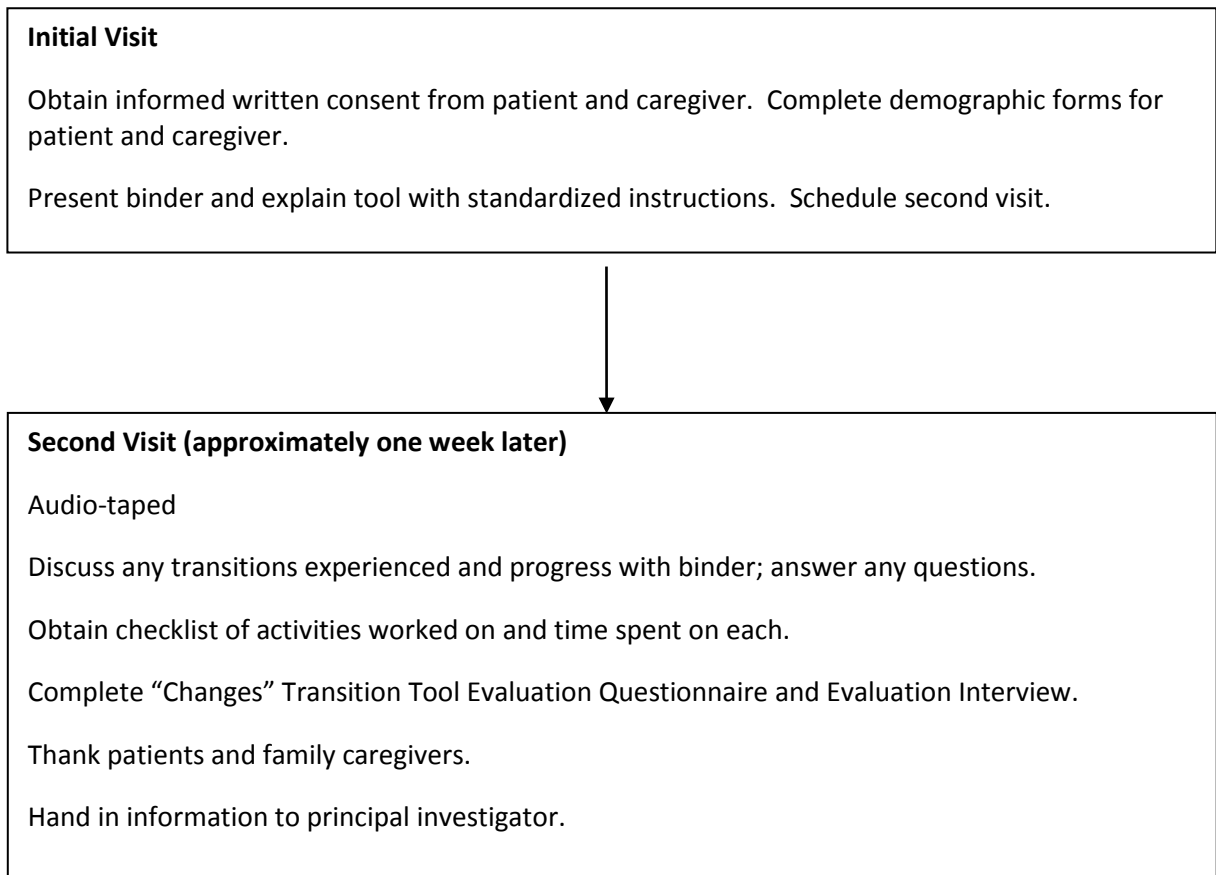


Figure 2 Data Collection Plan for “Changes” Transition Tool

The study was comprised of two visits, one week apart. The protocol of the initial visit was to obtain informed written consent from both the patient (Appendix B) and the family caregiver (Appendix C), complete the demographic form for both the patient (Appendix D) and the family caregiver (Appendix E), present them with the binder and explain the tool to both the patient and the family caregiver with standardized instructions (Appendix F), and lastly schedule a second visit. The second and final visit of the study was audio-taped and comprised of completing the checklist of activities and time spent on each activity within all sections of the binder (Appendix G); open-ended questions regarding changes experienced throughout the week, the binder, and any information they required were asked (Appendix H). Also, a questionnaire (Appendix I) and an interview (Appendix J) utilizing open-ended questions were completed to evaluate the use of the tool for palliative care patients and their family caregivers in rural communities both qualitatively and quantitatively.

Originally the research design for this pilot study used an embedded mixed methods (Quant + qual) design in which a qualitative data set provided a supportive secondary role to the quantitative data set. This design was to address the additional aims of assessing study protocol

procedures, evaluating how “Changes” may affect hope and quality of life for patients and their family caregivers as well as determine the ease of use, feasibility, and acceptability of the transition tool. This original research design had a study protocol of four weeks in length comprised of four visits one week apart (Appendix K). Following the data collection of three dyads of study participants using this original protocol, it was recognized that for the population being studied, the originally conceived four week time frame of this study was not realistic. The patients being referred to the study were too sick from their advancing illness to complete the entire four weeks or they felt that the four week protocol was too overwhelming to commit to; both being reasons cited regarding recruitment and retention issues. As the study progressed and as this knowledge was gained from researching the palliative population, the research design was adapted to the circumstances arising from recruitment and retention of study participants. The pilot study was then amended in consultation with the co-supervisors and thesis committee to the two week research design. Considering this was a pilot study, ample knowledge was gained about what is feasible and what is not in relation to researching the palliative population, especially regarding study length. With that in mind, the study length decreased to two visits one week apart. Throughout the entire study and across all of the collection sites, the overall common piece of evaluation for the transition tool “Changes” and the study protocols became the checklist, the questionnaire, and the interview utilizing open-ended questions to evaluate the use of the tool for palliative care patients and their family caregivers in rural communities both qualitatively and quantitatively.

3.2 Sample

The initial inclusion criteria for palliative patients were: 1) men or women, 2) 55 years of age or older, 3) residing at home within the rural area of the participating health regions or self-define as rural, 4) diagnosed with a terminal illness and receiving services from the rural palliative home care program in one of the participating health regions, 5) English speaking, 6) free of any cognitive impairment as recorded in the participant’s health chart that would hinder completion of the study, 7) not be participating in another research protocol, and 8) have a working telephone to enable the research assistant to contact participants. As the study progressed, the age of the palliative patient was later decreased to 18 years of age or older in consultation with the co-supervisors and thesis committee. This decrease in age for the inclusion criteria of the palliative patient was an attempt to increase recruitment of patients to the study. The inclusion criteria for family caregivers were: 1) identified by palliative patients as a significant caregiver, 2) men or women, 3) 18 years of age or older, and 4) English speaking.

A purposive sampling technique was employed for this pilot study. A sample size of 10 patients and their family caregivers as the goal for this pilot study was based on recommendations for pilot sample sizes by Birkett and Day (1994). However, utilizing the interpretive description methodology, it is recognized that representation is not concretely achievable based on numbers alone and that in reporting any study findings, it must be clear what the sample is reflecting (Thorne et al., 2004; Thorne, 2008). Using the strategy of

purposive sampling ensures that the pilot study findings produced will be reasonable to rural palliative patients and their family caregivers (Thorne, 2008). Therefore, the number of participants for this pilot study was set at 10 dyads recognizing it to be a somewhat arbitrary number while at the same time recognizing that this study is a pilot and that a larger scale study will be necessary in the future.

3.3 Setting

The pilot study took place in three data collection sites. The first site was the rural area of the Saskatoon Health Region surrounding the cities of Saskatoon, Saskatchewan and Humboldt, Saskatchewan, a large centrally located health care region in the Western Canadian province of Saskatchewan. The second data collection site was in the rural area of the Prince Albert Parkland Health Region surrounding the city of Prince Albert, Saskatchewan, a northerly located health care region in Saskatchewan as well. The third data collection site was the rural areas excluding the cities of Edmonton, Calgary and Lethbridge and their surrounding area, all of which are located in Alberta, a Western Canadian province. These areas contained rural Telehealth clinics affiliated with the Department of Pain and Symptom Control, Cross Cancer Institute in Edmonton, Alberta.

For the Saskatchewan sites, the Saskatoon Health Region and the Prince Albert Parkland Health Region, the pilot was conducted predominantly in the homes of palliative care patients receiving services from the rural palliative home care in these regions. Data was obtained by telephone and audio taped for the Alberta sites.

3.4 Data Collection

Data collection involved obtaining consent from the palliative patient (Appendix B) and the family caregiver (Appendix C), the completion of a demographic form for the palliative patient (Appendix D) and for the family caregiver (Appendix E), the completion of a checklist of activities and time spent on each (Appendix G), the completion of a questionnaire – “Changes” Transition Tool Evaluation Questionnaire for Patients and Family Caregivers (Appendix I) and qualitative open-ended interview guides (Appendix H and Appendix J). After receiving the name of each referral ensuring that each referral knew they were on the palliative service, a telephone call was made by the researcher as soon as possible to further discuss the study and inquire if the patient and their family caregiver were willing to set up an initial visit. All interviews, except one telephone interview, in Saskatchewan were conducted in the patient’s home by the researcher and kept to a maximum of 60 minutes out of respect for the participant’s energy level and time. All dyads of patient and family caregiver were interviewed together at each visit, except the above mentioned telephone interview in which only the patient was interviewed. The second interview for the Saskatchewan participants was audio-taped. All interviews in Alberta were conducted over the phone and audio-taped by the researcher with the interviews being completed within the one hour time frame as well.

3.4.1 Demographic Form

Upon completion of the consent forms, a demographic form for both the patient (Appendix D) and the family caregiver (Appendix E) was completed. Information regarding age, gender, marital status, ethnicity, residency, occupation, education, religious preference, self-reported health status, primary diagnosis and date of that diagnosis, date admitted to palliative care, other concurrent diseases, medications currently used, and current health services was collected from the patient. The family caregiver information included the previous pertinent information as well as information regarding income, medical health history, relation to patient, time spent caring for the patient as well as length of time care giving since the palliative diagnosis.

3.4.2 Checklist of Activities and Time Spent on Each

In table form, each section of the binder and the corresponding activities in each section is labelled on this checklist (Appendix G). The patient and family caregiver were given this form at the initial visit to complete throughout their week spent with the binder keeping track of who, the patient, the family caregiver or both, spent time on a certain activity keeping track of the amount of time devoted to each. At the second visit, the researcher then went over this completed form with the patient and family caregiver to ensure its completion.

3.4.3 Interview Guide for Palliative Patients and their Caregivers

Following the completion of the checklist, three open-ended questions were asked of these dyads at the second visit. They included any changes experienced in the previous week, their thoughts on the binder including if it was helpful or not, and finally if they had any questions or comments regarding the binder. This interview guide can be found in Appendix H.

3.4.4 “Changes” Transition Tool Evaluation Questionnaire for Patients and Family Caregivers

This questionnaire was utilized to ascertain both qualitatively and quantitatively an evaluation of the “Changes” tool. Each of the three questions asked in this evaluation employed a Likert scale. Additionally, a space for comments was available regarding each question as well as at the completion of the questionnaire. Appendix I contains the “Changes” Transition Tool Evaluation Questionnaire for Patients and Family Caregivers.

3.4.5 Evaluation Interview Questions for both Patients and Family Caregivers

This interview contained three questions regarding study participation and six questions regarding the “Changes” tool, as well as one question asking for any suggestions regarding either topic. The interview guide for this evaluation interview was: What was it like to be part of this study experience?, Was there anything that helped you to participate?, Was there anything that hindered your participation?, What did you like best about the “Changes” activities?, What did you like least?, Did working on the activities help with your awareness of your transitions?, Did

working on the activities help you connect with others?, Did working on the activities help you redefine what is now your normal?, Did working on the activities change your hope or quality of life?, and Do you have any suggestions?

3.4.6 Initial Impressions and Thoughts Following Each Visit

In order to capture the entire experience of each participant and their family caregiver, the researcher in Saskatchewan kept field notes of any impressions or thoughts following any contact with a palliative patient or their family caregiver either by phone or in person. Included in this log was the setting of the visits, describing the environment; the interaction between participants, both verbal and non-verbal, as well as any other information that was shared through the interviews. Although this shared information may not have pertained directly to the research, it was issues and feelings that were weighing heavily on either or both of the patient's and caregiver's minds at that time and they were wishing an attentive ear to listen to their cares and concerns of the day and the future. In Alberta, audio taped field notes included similar information.

3.5 Data Analysis

Quantitative data was entered into SPSS 18. Qualitative data was transcribed by an experienced transcriptionist and checked with audiotapes for accuracy. The methodology of interpretive description was utilized for data analysis of the qualitative data collected. In using the interpretive design, the purpose of data analysis is to identify themes and categories in the data (Thorne, 2000). In Saskatchewan, visit two of the study protocol was audio taped and transcribed verbatim. Immediately after each visit, as well as after any telephone contact with either the palliative patient or the family caregiver, the researcher made field notes reflecting on the visit or telephone conversation. Before any formal data analysis began, the researcher was involved intimately with the data by gathering data during each visit, reflecting on the data obtained during the interview or any phone calls while making field notes of the same, and listening to the audiotapes of the visits comparing them to the transcripts line by line to correct any errors that may have occurred in translation. Intensive immersion with the data was undertaken. With the research question in mind, the audio tapes of the visits were listened to and the transcripts of the visits as well as the field notes were read to gain an overall impression. The data was then analyzed to identify themes and categories within the data. Associated themes and categories were placed together and coded. The data was reanalyzed until no new themes or categories could be identified. This process is what Lincoln and Guba (1985) refer to as constant comparative analysis with concurrent data collection. This involved the simultaneous process of data analysis with the collection of data, which meant that analysis began on the completion of the first interview and continued with each subsequent interview.

The themes and categories that were shared by most participants were placed together and coded as interpretive description requires. The intensive reading and reflecting of the data, with

the goal of sorting through the ideas that are fundamental to an understanding of the phenomenon versus common and even important ideas, but which are essentially part of different questions was undertaken to decide which thematic patterns among and between individual patients and family caregivers were important to place together and code (Thorne, 2008). In Alberta, each phone call was audio taped and transcribed verbatim with data analysis occurring in the same way as with the Saskatchewan data. The themes and categories from each set of data was then compared and contrasted for similarities and differences.

A variety of strategies were used to enhance the rigor of the research process, including carefully checking the transcripts against the audio tapes line by line for errors in translation. As well the transcripts were analyzed line by line, making notes in the margin regarding themes and categories, reviewing the field notes with the transcribed interviews, and carefully identifying potential biases by the researcher throughout the research process.

With regards to the quantitative data analysis, the evaluation of the “Changes” transition tool employed a Likert scale for eight questions. These scores were analyzed using descriptive statistics. In consultation with a statistician, considering a sample size of ten patients and their family caregivers, descriptive statistics was chosen as the best means with which to relay findings especially when testing a tool (G. Lang, personal communication, September 23, 2009). The descriptive statistics described the results of the evaluation questions into mean, ranges of scores and standard deviation. Measures of central tendency such as the mean describe the central characteristics of a data set, while the range of scores and standard deviation measures the variability of a data set (Vincent, 2005). Qualitative and quantitative analysis were integrated in the reporting of the findings.

3.6 Ethical Approval

Prior to commencement of data collection, a proposal was submitted to the University of Saskatchewan’s Behavioural Research Ethics Board. Ethical approval was obtained on September 17, 2009, re-approved on February 23, 2010 and January 17, 2011 (Appendix L). A request was initially made to conduct research in the Humboldt, Saskatchewan area under the advice of the Palliative Care Manager of the Saskatoon Health Region. A letter of official approval, dated October 1, 2009 was received to conduct the research in the Saskatoon Health Region, which included Humboldt, Saskatchewan (Appendix M). The Palliative Care Clinical Coordinator-Rural located in Humboldt agreed to be the contact person for the researcher to recruit participants. Six referrals were made from this part of the region. A referral made on June 18, 2010 became the first palliative patient agreeing to participate in the study on July 5, 2010.

As prior approval was obtained to conduct research in the Saskatoon Health Region, the Manager of Client Patient Access Service (CPAS) and the three Rural CPAS Palliative Care Coordinators working in the area surrounding Saskatoon, Saskatchewan agreed to be the contact

persons for the researcher to recruit participants. Two referrals were made from this part of the region. The first referral was made on October 8, 2010 with that patient becoming the second participant on October 13, 2010; the second referral was made on December 23, 2010 with that patient becoming the third participant on January 13, 2011.

A request was made to conduct research in the Prince Albert, Saskatchewan area, the Prince Albert Parkland Health Region. The Director of Home Care, the Palliative Care Nurse, the Palliative Care Assessor and the Rural Home Care Managers agreed to be the contact persons for the researcher to recruit participants following ethical approval from the Prince Albert Parkland Health Region. A letter of official approval, dated April 12, 2010, was received to conduct research in the Prince Albert Parkland Health Region (Appendix N). No referrals and consequently no enrolments were made in this region.

An ethics application was made to the Alberta Cancer Research Ethics Committee and was approved June 30, 2010 (Appendix P). Several rural Telehealth clinics associated with the Department of Symptom and Palliative Care at the Cross Cancer Institute in Edmonton, Alberta were the sites for recruitment. Of the 27 referrals received, six referrals were enrolled and became study participants. The Behavioural Research Ethics Board at the University of Saskatchewan was kept abreast regarding any changes in location of the research. No other changes were made to the research protocol at this point.

3.6.1 Ethical Procedures

Prior to commencement of data collection from any individual participants, written informed consent was obtained from each palliative patient (Appendix B) and their family caregiver (Appendix C). Each study participant and the researcher signed two copies of the consent form and a copy was left with each participant. The consent form, one for the palliative patient and one for the family caregiver, was thoroughly explained to each participant emphasizing the confidential aspect of any data obtained. All data was kept confidential in a locked file that only the supervisor and researcher were able to access; with the data being stored for five years as is the University of Saskatchewan policy. The consent forms were kept separately from the data. Code numbers were assigned to each participant. The participants were informed of the research study purposes, study procedures, any benefits or risks that may be inherent to the study, and that they could withdraw from the study at any time without penalty as outlined in the consent form. The participants had an opportunity to ask any questions at that point and at any point throughout the study. After consent was obtained, data collection commenced.

The original study included the aims of addressing the outcomes of hope and quality of life and what effect if any “Changes” would have with regards to palliative patients and their family caregiver’s quality of life and level of hope. Permission was granted by Dr. Kaye Herth on July 31, 2009 to use the tool she developed to measure hope, the Herth Hope Index (Appendix P). Permission was granted by Dr. Robin Cohen on August 23, 2009 to use the tools she developed,

the McGill Quality of Life (Appendix Q) and the Quality of Life in Life Threatening Illness-Family Carer Version (Appendix R), to measure quality of life.

In light of the recruitment and retention issues that became apparent while conducting the study, a study amendment was applied for to both the Behavioural Research Ethics Board at the University of Saskatchewan on November 26, 2010 and Alberta Health Services on November 22, 2010 which included a revised consent form for both the palliative patient and their family caregiver. Due to the recruitment and retention rates, changes were proposed for the inclusion criteria and the data collection. The inclusion criteria of age for the palliative patient was proposed to be changed to 18 years of age and older with the remainder of the criteria unchanged. Based on the focus of the pilot study having the purpose of evaluating the transition tool “Changes” for feasibility, acceptability, and ease of implementation and utility, the data collection time was proposed to decrease to one week following the initial visit. Data collection would no longer include baseline and pre and post measures at week 1, 2, and 3 on hope and quality of life. The checklist of activities and time spent on each activity, open-ended questions regarding any changes experienced, the binder or any information sought, as well as the “Changes” Transition Tool Evaluation Questionnaire for Patients and Family Caregivers and the open-ended evaluation interview, all of which had previously been approved would be completed at week one. The study amendment was approved on December 1, 2010 (Appendix S) by the Behavioural Research Ethics Board at the University of Saskatchewan and on December 8, 2010 (Appendix T) by the Alberta Cancer Research Ethics Committee.

3.7 Recruitment

Following ethical approval from the University of Saskatchewan Behavioural Research Ethics Board, the Saskatoon Health Region and the Prince Albert Parkland Health Region, recruitment for study participants took place in the rural areas of the two health regions in the western Canadian province of Saskatchewan. A total of eight dyads of participants were referred in Saskatchewan with three dyads participating in the study. Palliative patients and their family caregivers were also recruited from the rural areas in the western province of Alberta (excluding the cities and surrounding areas of Edmonton, Calgary and Lethbridge) following ethical approval from the Alberta Cancer Research Board. One hundred thirty three palliative patients were eligible for the study in Alberta with 27 palliative patients agreeing to speak with the researcher. Of these 27 patients, 11 dyads of palliative patient and family caregiver were initially enrolled. Two dyads of patient and family caregiver dropped out of the original study protocol, three dyads dropped out of the amended study protocol, and four dyads, one palliative patient and one family caregiver completed the study protocol to varying degrees.

3.8 Study Procedures

The following changes were made to the study protocol to deal with recruitment and retention issues as the study progressed: 1) The inclusion criteria for the patient was broadened

to include those 18 years of age and older, 2) the length of data collection decreased from four weeks to two weeks, and 3) recruitment initially was to be in only one health region and ended up being in three health regions. In Saskatchewan, the number of referrals in the health region first utilized for the study was low, necessitating the use of a second health region in the same province. This health region provided no referrals of potential study participants. Therefore, the third health region in Alberta was employed in the attempt to increase referrals for the study. In Saskatchewan, referrals for study participants were low, however once they were in the study retention was high. The problem was different regarding study participants in Alberta. That province provided numerous referrals; however, the retention rate was low.

Only one patient made a comment on the actual study procedures. This patient stated that even under the new study protocol, the study needed to be simplified and condensed. There was no further elaboration on this comment.

CHAPTER FOUR: FINDINGS

4.1 The Sample

The sample was comprised of seven dyads of palliative patients and family caregivers, as well as one palliative patient and one family caregiver for a total of 8 patients and 8 caregivers. Seven patients were diagnosed with advanced cancer and one patient with advanced chronic obstructive pulmonary disease. Four of the patients were female and four patients male. The age of the palliative patients ranged from 52 years to 85 years of age, with a mean age of the patients being 64.4 years (SD 12.7). The length of time the palliative patient participants received palliative care services ranged from one month to 48 months, averaging 12.8 months (SD 17.8).

The age of the family caregivers ranged from 55 years to 71 years of age, with a mean age of 65.5 years (SD 6.38). Five of the family caregivers were females and 3 family caregivers were males. Their relationship to the palliative patient was wives (4), husbands (2), one was a son and another one a friend. The family caregiver study participants reported care giving 7 days a week averaging 14.75 hours per day. One dyad was involved in a previous research study, one patient was involved in a previous breast cancer research study and one patient was waiting for an appointment regarding a future clinical trial. All participants, both patients and family caregivers were Caucasian.

4.2 Evaluation of “Changes”

The quantitative data set provided a supportive secondary role to the qualitative data set. The data gathered quantitatively was the time spent with the tool as well as the evaluation questionnaire scores.

4.2.1 Time

Patients and family caregivers estimated the total time spent with the tool during their study participation. The time spent with the tool included reading it, skimming through it, participating in the activities within it and discussing the binder with others. The study participants reported time spent with the tool ranging from 15 minutes to ten hours with a mean time of 183 minutes (SD 239.2).

4.2.2 Evaluation Questionnaire

At the final visit with each study patient and/or family caregiver, a final evaluation was asked to be completed. Participants were asked 8 questions using a Likert scale for their answers: 1= Fully disagree, 2= disagree, 3= neutral, 4= agree and 5= Fully agree. Table 1 contains the quantitative evaluation of the results from the questionnaire.

Table 1 Quantitative Evaluation

N=7 dyads, 1 patient, 1 caregiver	Questions	Mean STD. Score (min-max)
Ease of use	1. Were the directions clear?	4.4 (0.5) (4-5)
	2. Were you sure of what you were expected to do?	4.4 (0.9) (3-5)
Feasibility	3. Did you have the energy to complete what you wanted to?	3.2 (1.1) (2-5)
	4. Were you able to complete the activities you wanted to?	3.0 (1.8) (1-5)
	5. Did you have time to carry out the activities you wanted to?	4.0 (1.1) (3-5)
Acceptability	6. Do you feel working with the “Changes” binder increased your ability to deal with transitions?	3.7 (1.2) (2-5)
	7. Would you do it again?	4.3 (1.1) (3-5)
	8. Would you recommend to someone else?	4.4 (0.8) (3-5)

As the qualitative and quantitative data were integrated at the results level, an explanation of the quantitative results from Table 1 is described in the sections below.

4.3 Evaluation Questionnaire Qualitative Data

4.3.1 Ease of Use or Ease of Implementation

The intent of ease of use or ease of implementation for the purpose of the study is defined as can a patient or family caregiver work with the tool or complete the activities in the way in which they were developed. When asked during the evaluation of the tool, all of the patients and all of the family caregivers found the directions to be clear: “I find the directions were very clear”, “I find the directions really good” with no further elaboration made by any of the study participants. The data from the evaluation questionnaire (Table 1) regarding ease of use (questions 1 and 2) reported mean scores in the “agree” to “fully agree” ranges to suggest that the tool was easy to use. As one participant stated “My favourite part was just being able to grab it at any time” indicating the ease of using the tool.

However, throughout the study protocol, two patients did have minor difficulty with the directions pertaining to the tool initially. One patient stated that he found it difficult to use the binder; difficult to figure out what information is contained where. The first time he attempted to use the binder he had a hard time trying to understand how to use it asserting that “I can probably figure out answers better than I can reading that thing trying to figure out what to look up.” He said that having the researcher explain the binder a second time made a real “difference” to his understanding of how to use the binder. Another patient participant at times

had trouble understanding expectations in a couple of places in the binder and thought perhaps her mood or fluctuations was the best explanation for not understanding right away stating “..couple times I had a little trouble with the pathway... when I first went into it was not a good time. I can’t differentiate, but it might’ve been my mood or my health swing at the moment or...lack of concentration.” By reading those parts again she cleared up any confusion she had: “I just needed to sit down and re-read.”

This same patient and her family had in the past and as well at the time of the study, used a journaling technique as a communication tool to inform one another: “...we’re trying as a family, to everybody carry a book with them, even though we’re not together, every time we have a conversation, anything that – right, everybody’s writing their thoughts and stuff, we’re gonna sit down as a family and like kind of put together so we all know where everybody stands. We just wanna be informed of each other and like you know, be able to – that way I’m not trying as a patient who’s trying’ to get through this, tryin’ to handle the whole thing all on my own.” She felt the binder could be used in a similar fashion: “...this binder’s like my daytimer where I pull it all together and put it together.” Another patient specifically commented that using the binder helped keep track of medications: “Sure helped a lot the other day just knowing the pills and, you know, the regimen of taking the pills, that helped quite a bit. Additionally, this patient felt the binder assisted in keeping a history of medical appointments: “You’ve got them when you go back to see.”

Most of the patients and all of the family caregivers found the expectations clear. One patient furthered this by stating that she understood the binder to be a tool that she could basically take and use where or how she wanted to, not what she should be doing with it. She felt comfortable with using the binder in that way. Another patient echoed that by saying she was sure of what was expected to do with each activity, “...looking at it from each person’s perspective, it would-they could take out of that what they wish.”

4.3.2 Feasibility

With regards to the evaluation of the feasibility of the tool (defined as being practical and capable to put into effect for palliative care patients and their family caregivers, including making a difference), there were similar concerns across the study participants. Three patients and one family caregiver specifically cited lack of energy as the biggest hindrance to using the tool: “I just don’t have the energy level that I used to”, “And to sit for any length of time it just wasn’t something I could do. By the time I thought about it and wanted to do it my energy had gone. And it was all I could do to just keep myself going with doing what I had to do”, and “I, well I couldn’t sit down and do it all at once...little bits and pieces...I tire very, very easily...I don’t have a very high energy level, so to sit down and actually do something like this”. The range of scores for the evaluation question did you have the energy to complete what you wanted to (Table 1 question 3) was in the “disagree” to “fully agree” range suggesting that lack of energy was an issue.

The energy level for patients and family caregivers had a great effect on the use of the tool. The family caregiver stated she does not have the energy she used to, first noticing this decrease when she became an insulin dependent diabetic. Therefore, she found it hard to use the binder as well as be the caregiver for her husband and carry on her regular day to day activities. One patient was using the travelling health record, symptom tracking and medication list. She stated that under Everyday Hope many thoughts came to her. For many days she would not be able to do anything, but expressed feeling so good in even accomplishing one little thing. Then she would take on a bigger project like the activities in the binder and do them when she was able to do them: "I go many days not doing anything, but it feels so good accomplishing then one little thing...And then take on those bigger projects too, but, do 'em when you're able to do 'em." Then her energy level would catch up with her so she would have to prioritize her activities and carry out those ones in the binder that she chose to do or had time to do: "I've limited [the activities in the binder]. I just don't want to do all the ones that I thought, I used to do. They're not as important." Energy for her was the limiting factor and she only used the tool for short periods of time. She further stated that she will not continue to use the binder post study as she does not have enough energy "I just don't think I'll have the energy," is dealing with pain and feels sick. She does believe her family caregiver will use it for organization regarding medication "Gonna use it to switch over from just his papers on the medication to get them down" and her grown children will use it to keep up to date information on her, the patient: "You know, and almost use it like a homecare kinda information tool."

Another patient cited energy and lack of time as a major deterrent to using the binder. She felt her concentration was poor to complete the activities. It was difficult for her to be able to set everything else aside and sit down and do the sections she really wanted to do. During the course of the study her mother had a heart attack, her daughter had a baby and a friend from out of town came to visit thus limiting her time. A third patient also stated that she would work on the binder more fully when she "didn't have anything else to worry about." She felt with people coming and trying to get her out of the house and entertaining occasional overnight guests, she has not established a regular time to work on the binder. That as well as doctor's appointments, feeling poorly, nausea with chemotherapy treatments, low energy, a hospitalization for blood clots and then when feeling well, doing the accounting books for a charity, she mostly read the binder, thought about how she was going to answer the questions in the binder and organized the few notes she had made.

The patients and family caregiver developed strategies to get around their lack of energy in using the tool. The first patient decided to use the binder one section at a time and stretch it out so she would have the energy to use it as she tires out easily. The second patient did not have the energy to fill in some of the items so she had someone do it for her because she felt it was important stating, "When you are where you can't do it or have the strength to do it, then you have someone to do it for you 'cause it's so important." The third patient made quick notes regarding each section and inserted them into the binder going back to them and writing them out

in full detail when she had the energy to do so. The family caregiver only spent time with the binder on activities or sections she found important in short time frames when her energy level was adequate. Only one patient in the entire study stated she had energy to use the binder. She was able to complete some sections of the binder as she had a good energy level, but no time stating, “It all has to do with timing...I’ve been busy. I’m taking responsibility for myself but, I’m also taking time to smell the roses.” This patient was also busy with starting up a cancer support group, “Once a week we’re having a support group...it’s just the timing thing” as well as her normal day to day responsibilities. However, over the course of the last year, she has slowed down by choice stating that she is taking it easier and enjoying life's gifts. Life had increased meaning for her. By slowing down and stopping to smell the roses, this patient could keep her focus on that meaning. She states that “Everything means so much more to me now, because I know it can be gone tomorrow or the next day.”

Although the mean scores reflect that participants neither disagreed or agreed with their ability to complete the sections they wanted to (Table 1 question 4), they felt that they had time to carry out the activities (Table 1 question 5). The qualitative data suggested otherwise. When study participants were asked if they were able to complete all sections of the binder during the course of the study, most of the respondents faced difficulty with decreased energy as described by one participant, “By the time I thought about it and wanted to do it my energy had gone.” Other difficulties included a lack of concentration and generally feeling unwell. Lack of time, which included poor timing of the study for some participants, was also listed as a deterrent to completion of activities in the binder. “Between doctor’s appointments and that it’s been kind of hit and miss” and “It was this week. My mother had a heart attack, my daughter had a baby and I had a friend from out of town so...I didn’t have the time this week” are two examples of poor timing with real life events occurring during the course of the study. Lack of time either due to family commitments, packing for a change of address, community commitments, hospitalizations, doctor appointments, blood work, chemotherapy, nausea, occupational therapy, emergency room visits and difficulty in getting started were cited as reasons given by the patients and family caregivers for not using the tool with ease as exemplified from the following excerpts: “We haven’t had time” and “I am going to use it once I get some time to write things in there.”

Lastly, three patients were already using some type of formalized system regarding their health-illness condition. One patient was using the journaling technique as discussed previously, to assist family members to “be informed of each other” and thought the tool would be a good resource to keep data handy. She even took it to a drug trial screening appointment for a drug trial she was interested in being involved with although she had already developed a type of health record and a system to track symptoms. The second patient had a system in place for a travelling health record and a contacts list, as well as the use of a calendar. Also, a third patient had already developed a binder for appointments and medications with a file format of important documents as well.

4.3.3 Acceptability

The acceptability or the receptivity of the binder was overwhelmingly positive by both patients and family caregivers alike. Acceptability was defined quantitatively in the evaluation questionnaire as “Did they find the binder assisted them in dealing with transitions, would they use the binder again and recommend the binder to others.” Qualitatively, acceptability was defined as the value the binder had for the participants. The comment that most defines this finding was from a family caregiver who wished to be part of the study, but whose father, the patient, did not wish to participate. She commented that she was totally interested but thought her dad did not want to participate due to a “generational thing-doesn't find that kind of stuff important.” She went on to state, “Don't give up, keep trying, it is important to do this.” All of the patients and family caregivers felt the binder was important and worthwhile. Examples of quotes were “Each section, I think they all have benefit and value”, “This is something that's really, really important and can help them through some really tough times”, “I honestly think it is a good thing”, and “I am recommending it to everybody – when I go to these support groups, we bring it along like a little bible.” This data is consistent with the data from the quantitative evaluation (Table 1) that most participants would use the binder again (question 7) and recommend the binder to others (question 8).

A major finding about the receptivity of the binder was the timing of the implementation. Patients and family caregivers alike, in particular two dyads, one patient and one family caregiver, stated that the binder would have been most effective for them if it had been received at the start of their palliative care experience. As one family caregiver stated, “I honestly think it is a good thing....I was telling [the patient] this morning but I think it was almost too late. I wish we had something like that right to start with.” This would have enabled the binder to be utilized as events were unfolding during their time in palliative care. One dyad who had been on the palliative care service for ten months prior to receiving the binder felt that they had all the answers they required and the binder did not give them any new insight. They did further state that they felt it may be helpful to people new to the palliative care service. One patient stated, “I could have used this about two years ago, really used it. Two years ago with my first cancer diagnosis, I was really struggling and I think you know, the whole thing about hope and actually sitting down and listing how I was feeling-I think it would have helped me cope better with my feelings.” Only one patient thought that people might not be emotionally ready for the binder at diagnosis but it is unclear whether she also meant upon the inception of the palliative care experience. When this patient was asked about timing of implementation of the binder being at diagnosis she replied, “No, I think it would've knocked me down too much...And they, they did do the, some palliative...heads up, you know. I wasn't really ready then and I said I wasn't going to be, and it's been another year and a few months since then, but it might be that you're not ready to hear the words yet.”

Only three patients and one dyad specifically commented on their perception of using the binder to assist with transitions. One dyad felt that the binder did not increase their ability to

deal with transitions as they were through most of the transitions they perceived they would have to go through. The patient stated that due to the fact they had been on the palliative care service a long time, the binder did not provide assistance to them in dealing with transitions. However, two other patients had high hopes for the binder in future dealings with transitions. One patient hoped it would improve communication between her and her family as there had been difficulty in speaking with them at times in the past. The other patient was using the binder to tell her story and to relay to others such as family, friends, and even strangers that the binder can help them through some really tough times. She sums this thought up by saying “We’re building this booklet day by day, that when I’m gone, anybody...can pick up this binder...give them a little more idea that this is something that’s really, really important and can help them through some really tough times.” The third patient stated that the binder had helped her to sort of say to herself not to expect that she was going to be the way she was and that likely her present health will probably be as good as it is going to be. She adds that she is grateful for her state of health at the present and willingly accepts it and deals with it each day. The range of responses as to whether using the binder had helped them deal with transitions (Table 1 question 6) is supported by this data.

There were specific sections of the tool that were mentioned as being important to the study participants. One family caregiver was very interested in the travelling health record as a way of organizing the patient's appointments, test results, treatments past and present, as well as medications. One patient thought her family caregiver would specifically use the resources and travelling health record when she became less able to care for herself, “Something that I can see him using a lot would be the Resources section and the Travelling Health Record, cause he quite often takes me in, when I have to go into the hospital, so I can see him grabbing that.” One patient kept the resource data handy in order to save time and energy searching for numbers. This same patient intended to use the binder as a communication tool between family members; for example to record daily happenings, “It's for the whole family to access so that like if...I'm not able to do it on my own, my daughter could look into this binder.” She also stated that she wants to share the My Story section with her family and other people in similar situations to hers. Ultimately, the binder became important to her to consolidate all the information she has gathered to date, “This binder's way easier for me to handle. My family can at a glance just flip to that and everything that's necessary up to this point will be in each one.” She had plans to add more folders for medical unemployment insurance, federal disability, pain management, a dietary section and the Thoughts and Wishes section. Prior to receiving the binder, this same patient had been keeping a food diary, medication diary, and a thought diary as well as a list of contacts at the cancer clinic she was a patient at. She had been regularly updating her own system of health records including medications and appointments prior to receiving the binder. One other patient had already developed her own binder system as well as a filing system regarding her health.

Lastly, two patients' comments summed up why the binder had been so acceptable to them. The first patient stated that she understood the tool to be one in which she could basically use how she wanted to, not how she should use it, "From what I understand, it's basically where I want to take it, not what I should be doing, but where I want it to be." This approach made her feel comfortable with using the binder and not intimidated by it. She also felt it would be good for her husband, her caregiver, should the progression of her disease advance to the point where she would be unable to use the binder. She stated that even though he is not much of a reader or writer, the binder would be a good resource for him. The second patient felt strongly that the ill patient has enough stress and that the binder could help alleviate some of that stress: "We just wanna be informed of each other and like you know be able to-that way I'm not trying as a patient who's tryin' to get through this, tryin'to handle the whole thing all on my own. Well I mean you've got enough stress, I think, you know what I mean? This way, if I can open a book and say ok my problem today is I need some resource numbers of this particular." This participant felt that the binder could assist in taking some of the burden off the patient, lessening the patient feeling the need to have to try and handle everything on their own. She also feels that the binder is helpful in the sharing of information. This patient had no formal caregiver designated at the time of the study. However, her daughter and two of the patient's friends who have had cancer were using the binder together. This binder allowed the entire group to share information.

4.4 "Changes"

Five evaluation interviews were completed, with the data gathered being extremely helpful in revising the tool. One dyad of patient and family caregiver and four patients completed the evaluation interviews. The remainder of the evaluations were not completed either due to: the death of the palliative patient and the subsequent unwillingness on the part of the family caregiver to complete the evaluation, one dyads withdrawal from the study prior to the evaluation, and participants simply unable or unwilling to complete the evaluation with no reason given. The evaluation consisted of questions about the tool with regards to a) sections of the binder that were liked the best, b) sections of the binder that were liked the least or least used, c) assistance with becoming aware of transitions, d) assistance with connecting with others, e) help you redefine what is now your normal?, f) ability in changing hope or quality of life, g) thoughts or helpfulness, and h) suggestions to improve.

4.4.1 Sections Most Preferred

Regarding most liked sections of the binder: there were a variety of answers. Overall, the participants felt all the sections were useful. The only dyad interviewed felt nothing really stood out for them as most liked. One patient felt the Thoughts and Wishes section was her most liked as she could go to that section and find something uplifting. Two patients felt each section had benefit and value, "There isn't a part in here that I don't use or wouldn't use to be honest". One of those patients furthered this by saying that she liked the binder being physically present and

could look up something and read it, “My favourite part was just being able to grab it at any time and find something that's uplifting in it, and not necessarily the same thing every time – something in here uplifts me every time I get into the binder.”

4.4.2 Sections Liked the Least

In regards to the sections they liked the least, very few participants identified anything that they did not like. One dyad felt nothing really stood out in the binder as least used or liked. Three patients felt that they would use the included resources, especially the contact list, the least. One of those patients stated she did not feel she needed the resources or the contact list at the present moment, another patient already had a system in place for contacts and the last patient felt it was a duplication of information already garnished from home care. The fourth patient listed travelling health record as least used for her due to the fact that she had already developed one. She did feel however, that she would be able to combine the travelling health record in the binder with her already established system.

4.4.3 Awareness of Transitions

Very little data was obtained with this question. One dyad did not believe the binder had assisted them with becoming aware of transitions with no further elaboration given. One patient stated in response to this question, that spending time with the binder made her realize the possibilities it holds: “..sitting down and really reading it over and stuff, you realize what, what it can do for you.”

4.4.4 Connecting With Others

Only one patient elaborated on the usefulness of the binder in connecting with others. She felt that the binder may have helped her connect to three of her main supports; her husband, daughter and brother and helped them to share information. Her husband felt left out of her experiences because he was at work all the time and not with her throughout the day. As she said: “My husband made a comment not too long ago, he said, 'I feel so left out of this process' because he's at work all the time and not with me throughout the day and I'm really hoping that this will give him that feeling of connection.” She went on to say that he felt the binder may help him understand his wife's situation and be part of her process fostering discussion between the two of them. She also hoped the binder could act as a buffer for her brother to help him learn more and better cope with her terminal illness. Another patient participant felt the binder helped in connecting with others “Oh yeah. Yeah definitely”. One dyad felt it did not help in connecting with others as they said: “Some people may find it more helpful than we did”; both giving no further explanation.

4.4.5 Redefine What is now your normal?

Only one patient and the dyad were asked about the binder helping them to redefine their normal. The dyad felt it did not help them as they said: “Don't think so. No didn't change that much”. The patient felt the activities did assist her to redefine what is now her normal stating, “Absolutely! Without a question. And isn't it strange how your yesterday's normal is not today's normal?” She felt that today's normal may not be tomorrow's normal with life now being a constant flux. She had to come to terms with this as she was at the time of the study dealing with her second diagnosis of cancer. She had accepted the constant change revolving around “normal” and felt that the binder had helped her with this acceptance. “Your normal today may not be the normal tomorrow.”

4.4.6 Hope and Quality of Life

Of the participants (one dyad and two patients) who were asked about the binder's effect on their hope and quality of life, the dyad stated it did not change either and the patient stated it was hard to say what effect it had as she was not sure what the future held for her. One patient participant felt that the binder did increase her sense of hope and quality of life as she stated: “It's increased it.” She described how connecting with others, exploring her feelings about her diagnosis and by getting together with friends who are cancer survivors and working on it together had a significant impact on her hope and quality of life.

4.4.7 Helpfulness of the Binder

Regarding the response to helpfulness of the binder, overall the comments were that it was or would be very helpful. One patient participant stated simply that, “I think it is an excellent tool.” Another patient participant had also showed it to a registered nurse that works with home care. She said that this registered nurse also thought it was an excellent tool and was quite impressed with it. However, one dyad felt they already had the information from their home care nurse with the patient participant stating that: “When our home care nurse first started coming around, in fact she was the one who told us about things. Anything we needed to know or wanted to know she told us.” They had even completed a do not resuscitate order for the patient and felt they had dealt with all of the types of activities provided in the binder prior to starting the study. The home care nurse, in their opinion, had provided them with everything the binder could provide, but felt some people might find it more helpful than they did.

Another dyad of patient and family caregiver said they had scanned the binder for fifteen minutes prior to their last study visit and stated they had not had time to spend on the binder. The family caregiver of this dyad did feel that it was almost too late for the binder for them, that it was a good tool but that it would have been much more helpful at the very start of the disease progression: “I honestly think it is a good thing....I was telling [the patient] this morning but I think it was almost too late. I wish we had something like that right to start with.” Another patient echoed this dyads thought by stating that she could have really used the binder two years

ago. If she had received the binder when she was diagnosed and had it as her illness progressed it may have helped her: “Like I could’ve used this, about two years ago, really used it, cause two years ago I was really struggling and I think you know....I think it would’ve gone a long way to helping me cope better with my feelings. This tool would’ve been awesome, you know, and then have, and then progress with the tool and as you progressed.”

One patient participant felt it would have taken too much of an emotional toll on her to have been presented the binder when initially diagnosed as she stated: “No. I think it would have knocked me down too much.” She was not ready to hear the word palliative when it was first brought to her attention and she would not have been emotionally ready for the binder. “I wasn’t really ready then...you’re not ready to hear the words yet.”

4.4.8 Recommendations for Improvement

Some very innovative suggestions were given by two patient participants to improve the binder for patients and their family caregivers. The first patient participant suggested expanding the table of contents to include a small summary of each section so as to make the content clearer. She personally would like to see the binder more cancer patient specific. Also, she would like to have more information inserted about websites and what a person using the binder could expect to learn from certain websites. The second patient found the medication list and travelling health record excellent. She suggested adding a calendar to track medical appointments and thought some of the binder could be condensed, but did not state which sections. The other suggestion this patient made revolved around implementation. She thought that if there was little time anticipated between diagnosis and death, she was not sure that the binder would be beneficial versus if a patient had more time. She felt that if the patient was not at the acceptance stage of illness, she was not sure it would be a valuable tool. She also felt that the homecare service may be the best people to assess the need, the timing of introducing the binder to the patient, and the utilization. She stated: “Maybe homecare if they had the binder, they would know when it was time, if they saw that somebody needed help organizing everything, you know....”

4.5 Context

The pieces of information gathered regarding rurality and being a patient or family caregiver seemed to be one of acceptance as to how living in a rural area affects their lives, including their health care. Although being rural as a participant in this study did not seem to have a huge impact on the patient or family caregiver’s perception of quality of care or life, participants did express difficulties with access to services. One study patient stated that living in a rural location affected her ability to pick up her prescriptions or anything else she required as she was not able to drive anymore. She was still able to obtain anything she required, it just took more planning and the assistance of friends and family. Another patient, who has COPD, has frequent hospitalizations due to difficulty breathing. On one particular occasion being ill enough to

require hospitalization, he was treated as an outpatient because there were no beds available in the hospitals of the two largest centers nearest to their home. This led to increased driving for the family caregiver which was related to the researcher as a fact, an acceptance, with no complaints noted.

A third patient stated that living in a remote rural area involved lots of travel. From her family caregiver's point of view, his concerns regarding travel centered on the difficulty in finding his way around urban areas to get to appointments. One potential study participant, a family caregiver, who declined being part of the study stating he was overwhelmed, did emphasize that city driving for appointments and treatments was very stressful for him during an already stressful period of time.

4.6 Themes

The qualitative data was analyzed using the methodology of interpretive description. The researcher grouped together bits of data through immersion in transcripts and field notes in order to make meaning of the data and portray that meaning into themes. Using interpretive description the following themes were found throughout the qualitative data: 1) Overwhelming change, 2) Being taken care of, 3) Connections, and 4) Giving back.

4.6.1 Overwhelming Change

Overwhelming change was a common theme of many participants. For instance, some of participants were dealing with the progression of the patient's illness, other participants were moving from rural to urban areas due to the patient's illness and yet others were overwhelmed with the continuous nature of change in their lives. Examples of quotes were "It's funny how you, yeah you go along and not doin' a lot and then all of a sudden everything seems to get goin' so, yeah", "And isn't it strange how your yesterday's normal is not today's normal?", and "I guess now I've learned that I will just keep what happens when it happens and deal with it." Changes or transitions had become a big part of the study participant's lives.

One dyad (patient and family caregiver) was making a move from the farm to town necessitated by the patient's failing health. The palliative patient's inability to do things he once could was placing the burden of responsibility for the both of them on his caregiver, his wife. She did not feel she could maintain the yard in the summer and plough snow in the winter by herself now that the patient was unable to help out due to his failing health. The family caregiver was not looking forward to the move initially, but they did decide to make the transition of moving less disruptive by choosing to move to a closer smaller urban center versus a further away larger one in order to stay within the present home care staff's divisional boundaries. "That's why we were thinking of going to [the nearest center with a hospital] and I says God I don't want to start new home care workers cause I like the ones we've got here. " Initially the family caregiver was overwhelmed by packing for the move, but as the visits progressed throughout the study and the process of moving started, her anxiety seemed to decrease.

Another participant, a patient, was also beginning the transition of moving. She was having a friend help her clean out unwanted and excess items in her house. She stated that she did not need a house of her size, she couldn't do the winter shovelling anymore, and if she needed medications, she had a hard time getting them while living on an acreage. This patient will stay in her house as long as she can, but knows that she will soon have to move, "I know I've always said I would be here as long as I could. After when I can't then I know I'm going to have to go." She is unsure of the right way to go with regards to her next move. Specifically, she is unsure whether to buy a condominium or rent a condominium and wants to feel comfortable that she is making the right move, "All I need to know is which is the right way to go, buy something, rent something and then we'll let the rest go. And once I get that and feel comfortable that I'm making the right move, I'll be fine." At the time of her participation in the study, this was the biggest dilemma she was facing looking to the near future.

Another example of overwhelming change was the transition from wellness to disability in a very short time for one patient. This overwhelming change was compounded by the unpredictability of his illness for his family caregiver which led to tension and fighting between this married couple which was an uncommon occurrence for them. This transition included a role reversal for this dyad as well. The patient was unable to do all he used to, with his family caregiver now taking on his previous duties. The family caregiver willingly performed these duties stating: "You shouldn't have to worry about that now" on more than one occasion. However, it was obvious that the patient wanted to maintain his independence, but his health would not allow it creating great frustration for him. The patient was visibly upset by an Occupational Therapy consultation witnessed by the researcher. This patient did not want to deal with equipment that indicated his health was failing and would continue to do so. The patient and the family caregiver were both dealing with fear of the future, and fear of the unknown with many physical changes for the patient and lifestyle changes for both. They had not yet developed the communication or were afforded the time they needed to deal with the transitions in such a short period of time.

Another example of overwhelming change was the transitions that patients went through as their cancer progressed. For example, one palliative patient was coming to terms with the changes associated with cancer such as changes in his life, his thinking and his priorities. You could almost hear the laughter in his voice as he relayed the fact that instead of talking about combine harvesting as a general topic of concern, he was now talking about his bowel function. Another patient participant was dealing with one medical concern and one social concern as her cancer progressed. The first concern was recovery from a six day hospital stay dealing with blood clots in her lungs leaving her on oxygen at home to be used as needed. She was unsure of when to use the oxygen and when sitting down and staying quiet would be enough to overcome her shortness of breath. She did not want to become dependent on the oxygen right now as she knows that day will come soon enough. Her other concern revolved around travel and her illness. She wanted to fly to see her son, her friend and her brother with her brother being the

priority. He was having difficulty dealing with her illness and she wanted to go and see him to reassure him that she was alright. As she described: “Once he is forced to see me and see that I’m I’m looking ok. Uh. Then maybe he won’t be scared to come and see me.” She was concerned regarding transporting oxygen, the humidity of the city he lives in making it more difficult for her to breathe, and scheduling the trip between blood work and doctor’s appointments; all concerns related to her lung cancer metastases and progression of this cancer.

Each patient and family caregiver participant were dealing with the transitions from being well to being ill. Some dyads were slowly coming to terms with the changes this entailed and others were working at it. However, all participants described being overwhelmed by these changes to some degree. For example one of the patient participants was dealing with being diagnosed a second time with cancer. Both he and his family caregiver, at the time of the study, described being unable to prepare for the future based on their present situation. They knew this diagnosis would be harder to deal with as the outcome would not be as favourable as the first diagnosis because now they were in the palliative system. This overwhelming feeling was incapacitating their ability to make plans for anything other than taking one day at a time.

Only two study participants made a statement about the acceptance of their illnesses at the time of diagnosis. As one patient participant stated about the acceptance of his illness: “No nothing I can change. When I was diagnosed I knew there was nothing I could change. I knew I had to live with it and that was it.” Another patient participant relayed that she still wanted to be active. She stated: “Whatever it takes let me tell you, I am determined on that!” Both of these patient participants had been dealing with their illnesses for numerous years and had the benefit of time in dealing with the changes in their lives.

4.6.2 Being Taken Care Of

Many participants made comments about their experiences with the health care system. Two dyads of patient and family caregiver participants and one patient participant were very satisfied or felt the quality of health care they received was extremely good. One dyad, two patients and one family caregiver participants were very frustrated by the health care system for various reasons. All of the comments centered on the treatment they received both physically and emotionally with communication having a large impact on the feelings they had regarding the health care system.

One dyad of patient and family caregiver were very satisfied with the palliative care they received: “I’m very happy with the home care”. This same family caregiver participant had previously experienced a mother, father and three siblings all receiving palliative care services before their death. Similarly, she had been very pleased with the care they received. This present level of satisfaction with the palliative care service was so great that they decided to move to a smaller urban center from their farm even though there was no hospital present there. This move would allow them to receive services by the same home care nurse and home care

aides. Furthermore, the family caregiver participant stated, “That’s why we were thinking of going to the nearest centre with a hospital and I says God I don’t want to start new home care workers cause I like the ones we’ve got here.” They felt well informed with all of their questions answered. They felt so well informed that they could not think of one thing that would improve their care presently. Interestingly enough, this is the same patient participant, who during the course of the study, was treated as an outpatient for respiratory distress because no beds were available in the two largest centers nearest their home. This meant increased driving for the family caregiver when the patient was ill enough to be in hospital, yet no complaints were noted from either patient or family caregiver. The second dyad commented that the health care they received in hospital was excellent, “Well, you know, the care we got at the Cross was excellent,” further stating “completely satisfied with the place.” As well, the quality of health care was stated to be “extremely good” with no further elaboration made. One patient participant stated this regarding home care nurses: “I have to say it has made it easier for me this past winter just to know there was somebody there somebody that cared someone with knowledge as well as uh resource.” Ultimately, these dyads and patient participant felt they were being taken care of by the health care system.

The frustrations felt by some of the study patient participants centered on waiting room times, delays in tests being performed, test results being relayed in an untimely fashion, inadequate pain management, inaccurate diagnoses, complications of navigating the health care system, and the work of dying due to the health care system. One dyad of patient and family caregiver were frustrated by the system in having to see so many doctors for different health care concerns, stating: “Like I mean it’s just foolish how the cancer doctor want us to go to the family doctor for the pain medication.” At the time of their study visits, they were seeing or had seen in the previous month a family doctor, an oncologist, a haematologist, a neurologist as well as an emergency room physician. They felt frustrated as well by the amount of appointments and the difficulty they had making timely appointments, “And you can’t even get in to him half the time.” They were also frustrated by lengthy waiting room times especially when the patient was not feeling well. The family caregiver felt waiting to see a doctor for excessive amounts of time was physically demanding and wearing on the patient at a time when he should be concentrating on taking care of his health and well being. One family caregiver was unhappy as well with waiting room times seeing firsthand how hard it was on the patient when she was not feeling well. This same family caregiver was dissatisfied with the untimely manner in which the patient received test results leading the patient to worry about the results for much longer than necessary. She stated, “I wish the medical professionals would care more about their patients, because some day it may be them in the system waiting in waiting rooms and waiting for test results, not getting answers and getting the run around.” Similarly, one patient stated that worrying about the delay of tests being performed which could delay treatment and ultimately decrease survival time is not something patients should have to worry about. The frustration with the work of dying also came through with this patient. While experiencing pain, fatigue, and weight loss leaving her unable to work, she was undergoing radiation to shrink tumors and

chemotherapy for pain management. Simultaneously, she was trying to research the internet to gain knowledge regarding her diagnosis and possible treatment options as well as compiling the needed paper work of dying. Applying for disability benefits necessitated gathering copies of physician visits. Since making that application, she has asked for a copy of every health care visit, “Every time I go in and see a medical practitioner of any kind, I can request a copy of my visit at no cost, so then when this department of whatever, whatever phones me up and needs this for their records...I’ve got all the information right here.” The second patient was frustrated by the health care system before her diagnosis of metastases to the lungs from her primary cancer of the breast was properly diagnosed. Prior to this confirmation, she had been treated several months for wheezy bronchitis and was eventually hospitalized for investigations. She said the pain over those months was excruciating. The inability to feel better with the treatment she was undergoing and not feeling like she was getting any answers was frustrating. She stated emphatically that, “The pain was so excruciating as I had said all summer if that river hadn’t been ten kilometers away I’d have jumped” to end the pain. Once this patient was diagnosed properly and treated accordingly, she has been much more satisfied with the health care she has received.

The participants all experienced major transitions with a terminal diagnosis and felt the need to depend or rely on someone or something during this time of uncertainty and high stress. That someone or something is often the health care system they look to for guidance and reassurance. Poor communication made the participants at times feel they were just a number in the system. However, for some participants who experienced effective communication with health care providers, a feeling of being cared for, real or imagined left them with a lingering sense of satisfaction.

4.6.3 Connections

There was an obvious and important connection noted between all the patient and family caregiver participants especially when both were involved in the study. The log data and field notes, which included observations, initial impressions and thoughts regarding each study visit, as well as the interview data itself, provided information on the relationships of the dyads. For example, there were dyads that laughed and joked with each other, supported each other and had a deep appreciation expressed for one another. It was how they would look lovingly at each other, how they would treat each other with respect, how they would tease one another or how they would show concern for each other that came through as strong connections between patients and their caregivers. For instance, when completing the demographic form, one patient was asked if he was married and he answered yes and his wife added jovially “Happily!” This same wife relayed with compassion how her husband on more than once occasion had to wait in the waiting room for an excessive amount of time in her opinion to see a doctor and that “It was just terrible, he was so sick.” One patient felt support from his son, his live-in caretaker and friends and relatives dropping in and visiting. He stated that he had help, was cared for and felt “they want me around.” One patient felt uplifted by the support of friends, support that gave her

hope and made her feel less alone. This bond between the patients and family caregivers in this study is not always the case as one patient stated that she has observed the opposite with her friend's situations. She stressed that she had witnessed her friend's marriages destroyed; patients are in pain, things get more difficult and some people end up giving up on their marriages.

Within these connections between patients and caregivers, there was a difference between them in terms of roles. Patient's roles appeared to be dictated by their overall level of health and energy on a day to day basis. Some patients with longer illness trajectories such as the patient with COPD felt he had "All the time in the world." This same patient was not well enough to perform his normal activities but was not imminently dying either; a sort of holding pattern. Others felt well enough and that they had the desire to want to leave a legacy; to share their experience and information with others, "To share it with people at the Cross Cancer is what I would like to do." Some were tired during the visits, yet others would have liked to do more for themselves rather than the family caregiver doing everything, "She won't let me do anything other than self-care.", "I want to get back to being able to take care of myself." Some were able to express their feelings openly to their family caregivers being very emotional, crying as their death loomed; others stoic to the end with one patient participant stating he was "feeling okay, don't worry about me."

Several factors made relationships with others more difficult possibly decreasing their connections with others. One patient stated she felt she was on an emotional rollercoaster having cancer. One patient did not like when people told her "You should...." statements. Another patient appreciated the emotional support and care given to her by her family caregiver, a friend, but felt overprotected by her at the same time. The patient felt a lack of control in her own life: "Like she could drive you crazy on one hand like there for a while after I came out of well once I got started in chemo. It was you don't go out, you don't do anything". When she had been discharged home from the hospital after having been treated for blood clots in the lungs, she described how her family caregiver was constantly telling her not to go out of the house, calling her five times a day to make sure she was staying in. This participant stated that at that point in time she was so tired of looking at her same four walls. She just wanted to go out for a coffee or a drive or anything to just get out, but her family caregiver kept telling her no. She did readily admit that this was probably why she hasn't had a cold or any kind of viral or bacterial illness since she started treatment for her cancer. Most patient participants felt that other people do not know what they are going through resulting in varying degrees of feeling disconnected from others.

The data suggested that there was an overwhelming resilience in most of the patient participants that came from within themselves. One patient stated: "You have down times where you think Oh man this is so much to take in but I don't let that get to me. I just say yeah it is and Oh okay you've had your me me ten minutes now make yourself a cup of tea or phone your funny friend." Another patient participant stated that when the pain was controlled she felt "pretty good." She knew her prognosis was not good and that a cure was not possible so she was

determined to “live each day as it comes.” Yet another patient participant was determined to live, “I have decided I’m going to be determined and I’m going to make the grade here.” She said, “It’s going to take a long battle,” but that she would keep going on and participating in life.

The family caregiver participants on the other hand were busy taking care of tasks such as household maintenance, arranging medical appointments, driving to and from medical appointments, providing physical care and emotional support and they took their role seriously. Some knew the patients they were taking care of were palliative from diagnosis and it became very important to them, as well as to the patients that they take care of their family member, “Really, really important for him and for me...he really, really leans on me for support.” There were family caregivers that were present for the patient every day, “I have been here for him every day,” or those that made sure someone was there at all times, “I don’t leave the house unless there’s somebody here to stay with him.” There were times when one family caregiver would interrupt and talk for the patient during the interviews. The patient participant, wanting to talk for himself or be heard, would abruptly start a new but related topic only to ask his family caregiver for clarification. Family caregivers also felt overwhelmed at times needing someone to talk to, “I am so overwhelmed and felt like calling you. It has been so hard to see him like this,” but did not want to confide in the patient as they worried it would increase their burden.

The most prevalent overarching theme regarding patients and family caregivers was the importance of the strong connections between family and friends. One patient believed that friends in her generation (baby boomers) did not need to be in touch every day, “And to us growing up in those days, but you don’t have to have a friend that you have to be in touch with every day, every day. Sometimes you never see them till you need them and you know the moment you need them they’re there.” She felt that when a friend was needed, they would be there. It was a very big blessing to her to be able to call on her friends day or night. In the same way, family was very important to patients and family caregivers alike especially in times of trouble. One family caregiver felt that she did not need respite from care giving as she had a lot of family support. She put it aptly, “If not connected to your family, you rely on healthcare more, and it’s not always able to fill in the gaps [like family can].” These strong connections also contained the aspect of worry for the patients regarding those near to them. Two patients in particular had mentioned their concern for their brothers in dealing with their illnesses and subsequent fears of their death. One of those same patients as well was concerned for her grown son as he would have no immediate family left with her death. The importance of connections between family and friends for patients and family caregivers was very apparent during the palliative phase of the patient’s diagnoses.

4.6.4 Giving Back

Another theme common in the data was that of giving back or a sense of altruism in their circumstance. Three patients and two family caregivers, all women from unrelated dyads, each stated in their own way that one of the reasons they took part in this study was to help someone

else out whether in the present or the future by giving something back. One family caregiver who continued in the study even after the patient, her husband, had died stated “Well you know, if it helps somebody else, it’s well worth my time, so you know it’s not that, there’s other people, there’s hundreds of people going through the same thing.” Another family caregiver relayed “I just thought well if it helps somebody else out, so much the better.” A patient having a diagnosis of breast cancer with metastasis to both her lungs asserted: “I am glad to help out, if it means that it will help someone else further down the line.” One patient diagnosed with endometrial adenocarcinoma with abdominal metastasis said that she just wanted to help somebody besides herself having now gone down the cancer treatment road twice. She further stated that she, an ordinary person taking part in this study could mean so much to other people who may have no support. She said for some people, when dealing with emotional and physical changes, trying to gain knowledge can become overwhelming especially if they have no support or don’t know what to ask. Finally, a patient with ovarian cancer just wanted to give something back by being a part of any resource or study or anything to provide comfort. These people, in the midst of their illness and everything that encompasses a palliative diagnosis, were willing to reach outside of themselves to give back to strangers.

4.7 Summary

The findings of this study occurred in a rural context and the information gathered regarding rurality and being a patient or family caregiver seemed to be one of acceptance as to how living in a rural area affects their lives, including their health care. Issues of driving distances to services resulted in some participants moving in order to be closer to the services. The quantitative and qualitative data suggest that the “Changes” transition tool was easy to use, feasible and acceptable. The majority of the participants found the directions clear and found the expectations clear indicating they found the binder easy to use. Feasibility in this study was defined as being practical and capable to put into effect for palliative care patients and their family caregivers, including making a difference. The majority of the patients and their family caregivers found the binder to be feasible. Even though patients and their family caregivers cited lack of energy and lack of time as deterrents to the use of the binder, strategies were employed to get around their lack of energy. One could speculate that given enough time spent with the binder, participants would also develop strategies to implement its use at periods of downtime such as in waiting rooms or the delivery of chemotherapy to get around the issue of lack of time. As well three patients were already using some type of formalized system regarding their health care lending evidence to the binder’s practicality and capability of putting it into use. The majority of participants agreed that working with the binder would increase their ability to deal with transitions. As well, the data gathered indicated that most participants would use the binder again and recommend the binder to others. This as well as the overall positive nature of the value participants placed on the binder, suggests that the study participants found the binder acceptable. Acceptable in this study was defined as the value the participants placed on the binder as well as in response to the question, “Did they find the binder assisted them in dealing

with transitions, would they use the binder again and recommend the binder to others.” Recommendations for revisions included: the addition of calendars for the participants to use as they wish, inclusion of more resources such as websites of natural health products, expansion on the table of contents, and making the tool more cancer specific. The participants also gave insights into how the intervention may be helpful as well as more effective. Suggestions included that the tool may assist in communication between patients, family and health care professionals. Some participants felt that the timing of implementation of the tool be on admission to palliative care and that home care personnel may be in the best position to implement the tool.

Four themes emerged from the qualitative data including: Overwhelming Change, Being Taken Care Of, Connections, and Giving Back. Change or transitions had become a big part of the study participant’s lives including the adjustments involved with advancing along the continuum from well to ill or relocating to a new address to accommodate the consequences of a palliative diagnosis. Some participants were satisfied with the health care system and some were not. While participants were experiencing major transitions and looking to the health care system to support them, those supported through effective communication felt satisfied with their care. Even though connections between patients and their family caregivers were present, patients found that unless a person was diagnosed as palliative, it was hard for them to understand just what they were going through. The value placed on family and friends and their support was very important to both patients and family caregivers alike. The palliative patients displayed resilience in the face of their terminal illness and some of the patient participants felt very strongly in their commitment to wanting to help others by participating in this study.

CHAPTER FIVE: DISCUSSION

The purpose of this pilot study was to evaluate “Changes” for ease of use, acceptability and feasibility for rural palliative care patients and their family caregivers. The overall positive nature of the results suggests “Changes” has the potential to help rural older palliative patients and their family caregivers deal with transitions. Constructive recommendations regarding “Changes” as well as insight to auxiliary benefits of the tool was beneficial in revising “Changes”. The findings of this pilot study are unique as the literature suggests very little research has been undertaken in this area. Using interpretive description, the individual experience of each participant, both patient and family caregiver, contributed to the overall themes of: Overwhelming Change, Being Taken Care Of, Connections and Giving Back.

5.1 Evaluation of “Changes”

The data gathered from this pilot using a mixed method design was unique by the very nature that there is a general lack of research data available regarding interventions intended for rural older palliative care patients and their families. The qualitative data regarding the acceptability, ease of use and feasibility of the intervention tool was supported by the quantitative data. Utilizing both sets of data was beneficial in making revisions to the intervention tool through participant feedback.

The design of the original study procedures was not realistic and workable for the population studied. The recruitment and retention issues necessitated decreasing the palliative patient's age as well as the time frame of the study from four visits one week apart to two visits one week apart. Furthermore, even with this amendment to the study protocol, one patient felt that the study needed to be kept as simple as possible, a finding echoed by White and Hardy (2010) in their systematic review of patients and their relative's views on palliative care research. Consequently, in order to construct a more realistic and workable pilot study for palliative patients and their families, the study aim of addressing the potential effectiveness of the intervention tool concerning hope and quality of life was deleted from the study.

Throughout the course of the pilot study, all patients were undergoing changes and in the process were restructuring, reorganizing and assimilating these changes. Some participants were coming to terms with their situation, while others were unable to even commence this process as their feeling of being overwhelmed was incapacitating their ability to cope with moving forward. All participants were connecting with family and friends and felt that communication was essential to feeling that they were being taken care of. The redefining of normal for some participants was a constant evolution that they had decided they would deal with in a direct straightforward manner looking for realistic solutions in contending with issues arising from their illness. All of these findings provide support for the emerging theory of Navigating Unknown Waters (Duggleby et al., 2010).

5.2 Overwhelming Change

All of the participants in this study were dealing with change. These changes or transitions being dealt with at the time of the study centered on preparing for an uncertain future. Past research on transitions has predominantly focused on the transitions from cure to care (Bolmsjo, 2008) and health system transitions (Lawson et al., 2006; Back et al., 2008; Duggleby et al., 2010). Thus the results of this study broaden our knowledge as the transitions experienced in this study were all within the confines of the palliative care experience. Just as Khalili (2007), Schumacher and Meleis (1994), and Duggleby et al. (2010) found that transitions experienced by palliative patients and their families included changes in roles, relationships, loss, goals of care, physical health, and independence, so too did the findings of this study.

Some study participants described their dissatisfaction with the health care services they were receiving, thus adding to the difficulty in dealing with the changes they were experiencing. In a review of the literature on transitions and palliative care, Marsella (2009) relayed that fears surrounding an impending death, lack of time to prepare patients and families and insufficient information as factors affecting quality of care. Grunfeld et al. (2008) described poor communication between patients, families and care providers as a factor contributing to decreased quality of care. One dyad in this study had several factors affecting their care, specifically fear, lack of time to be prepared, and poor communication in their situation. The patient had only been on the palliative care service for one week at the initial study visit under the original study design protocol. The second visit was completed one week later and a third scheduled for the following week. The day before the third visit, the patient had a heart attack and he died three weeks later. This couple was overwhelmed with change in such a short period of time with the patient losing his independence due to his declining health. Thus, fear of facing an uncertain and unpredictable future resulted in arguments which were atypical in their relationship. They had not yet developed the communication they required in dealing with this evolving situation. This couple spent very little time with the tool due to doctor's appointments, chemotherapy, coordination of palliative care services, and the patient feeling unwell. This family caregiver was one of the study participants who stated that receiving the binder at the time of her husband's diagnosis would have been more beneficial for them. She felt that the binder was a good thing, but almost too late for them.

According to an ethnographic study on the "good" rural death by Wilson and colleagues (2009) one of the most important beliefs they identified with rural people was that dying persons should be cared for and allowed to die in their home communities. This aspect of palliative care was identified with these study participants as well. For example, one dyad and one patient were preparing to move from their rural location to an urban center. The dyad was moving to an urban center for easier access to medical care for the patient, as well as the family caregiver's inability to continue to be the patient's caregiver and take care of their home and yard which included grass cutting in the summer and snow plowing in the winter. The urban center was only minutes away from their rural location and was still within their circle of what would be

considered their home community. Additionally, their son was moving into their farm home, so the connection to their family farm would still be there. As the father stated, “Not that far away. Not selling so.” The other patient was moving to an urban center less than a ten minute drive from her present home for easier access to medical care and essential items such as prescriptions and groceries. This patient lived alone and felt that taking care of her large home and yard was beginning to be outside her capabilities. Even though both of these examples involve a move from rural to urban, they were still within the boundaries of their home communities. In both cases, these moves are examples of change deemed necessary to address the patient’s palliative diagnosis.

One dyad decided to make the transition of moving rural to urban less disruptive to their lives by choosing an urban center that would enable them to stay with their present home care staff. The patient and family caregiver were “very happy with the home care.” Therefore, even though this dyad was making a rural to urban move, the actual destination of their move was very much influenced by the importance they placed on the primary health care professionals who provided care to them. This recurring theme was also described in the first published systematic literature review in the field of rural palliative care (Evans et al., 2003). The authors found that primary care professionals such as home care nurses were important to the delivery of palliative care services in rural areas.

5.3 Being Taken Care Of

Many comments were made by participants regarding the health care system. Study participants expressed frustration with the health care system for various reasons. Lengthy waiting room times, delays in tests being performed, delays in test results being given to the patient, inadequate pain management, inaccurate diagnoses, difficulty navigating the health care system and compiling the paperwork of end of life were a few reasons given contributing to their frustration. Royak-Schaler et al. (2006) found in their research on family perspectives regarding health care provider communication about end of life care with terminally ill cancer patients and their families, that satisfaction with their end of life care experiences was associated with the quality of communication received. Furthermore, they state this finding is in agreement with previous research into communication among patients, families and health care professionals (Hanson, Danis, & Garrett, 1997; Wenrich et al., 2001, 2003 as cited by Royak-Schaler et al.).

Good communication between health care professionals, the patients in their care, as well as their family members is widely thought to be a key element in providing high quality end of life care (Cherlin et al. 2005). Heyland and colleagues (2006) found that effective communication was one of the most important elements related to quality end of life care in a study surveying patients with advanced disease and their families. Whereas, research has shown that poor communication between health care providers, patients, and their families is associated with dissatisfaction with care (Grundfeld et al., 2008).

Although the positive benefits of good communication has been discussed in previous literature, the feeling of being taken care of through effective communication has not been previously identified in any research studies of palliative care patients and their families. Effective communication was essential to patients and their families feeling well cared for. When there was communication breakdown or lack of communication, patients and their caregivers did not feel well taken care of.

5.4 Connections

The connection between patients and their family caregivers was a very supportive one with great importance placed on its value to each participant. This finding is well documented in the literature. The quality of life of palliative patients may be severely compromised without the ability to fulfill their preferences through the support of family caregivers (Hudson & Payne, 2011). Furthermore, caregiver's support can improve the patient's care and enhance their well-being while at the same time gain positive outcomes from this role (Hudson & Payne). Hudson, Thomas, Quinn, Cockayne, and Braithwaite (2009) state that without this family support, palliative patients would not be able to remain at home if that is their wish, or could be at higher risk for dissatisfaction due to unmet needs.

The patient's roles and relationships prior to and when admitted to palliative care were often quite different dictated by their overall level of health and energy on any given day. This change in roles has been documented in the literature. Khalili (2007) describes palliative patients giving up roles in the family as their illness progresses with family caregivers taking on new roles while at the same time maintaining prior roles and responsibilities. Duggleby and Berry (2005) describe a palliative patient's role loss as a teacher due to extreme fatigue and her inability to continue working. Schumacher and Meleis (1994) relay how changes occur in roles and relationships due to transitions which in the case of a palliative patient is the health-illness transition.

There were findings in this pilot study that could be interpreted as ways in which palliative patients may feel disconnected with others. One participant described having cancer as an emotional roller coaster that can only be felt by those diagnosed with a terminal illness. One participant expressed her dissatisfaction with people not in her situation telling her how to manage her life by "You should" statements. Another participant expressed her perceived lack of control in her life due to her family caregiver insisting she stay home for protection against viral and bacterial illnesses while undergoing chemotherapy. Khalili (2007) uses the same "roller coaster" terminology to describe the patient diagnosed with malignant brain tumors and their families' feelings of great uncertainty, fear and hope from the time of diagnosis. However, these findings had not been identified in previous research with palliative patients.

Research with palliative participants has not described specifically the resilience portrayed by patients in this study. Some participants accepted their diagnosis from the very start

emphasizing they would continue to live in spite of the diagnosis. Other patients stated they did feel depressed at times, but that they carried on. Yet others knew they were going to die, but with their pain under control they felt they could continue on living day to day and be satisfied with that. Finally one patient expressed she would continue to live and adapt to her circumstances, participating in life without focusing on her death.

Family caregivers play a critical role in providing major assistance with care provision in the home. In this study, family caregivers were pivotal in providing physical and emotional care to their loved ones. Although the family caregivers at times became overwhelmed, they all wanted to take care of the palliative patient and did so willingly. Waldrop, Kramer, Skretny and Milch (2005) reported that caregivers have greater life satisfaction and a sense of reward even when care is demanding. Family caregivers provide physical and emotional support and care to their loved ones as they face devastating losses that negatively impact the quality of life of both patients and caregivers (Family Caregiver Alliance).

The importance of connections is found in previous research findings in patients with advanced disease and the palliative population. Family support is one of the hallmarks of palliative care (Hudson & Payne, 2011). Family members play an essential role in the care of dying patients (Bolmsjo, 2008). Duggleby et al. (2010) found that connections between patients, families and friends assisted in dealing with the uncertainty and change of distressing transitions, making those connections even closer than before. It is the connection to others that gives meaning to the lives and deaths of patients and caregivers.

5.5 Giving Back

Participants stated in their own way that part of the reason they were taking part in this study was to help someone else out whether in the present or the future or to give something back. The literature widely supports this sense of altruism. White, Hardy, Gilshenan, Charles and Pinkerton (2008) report that over 75% of 100 patients and their caregivers surveyed expressed altruistic views regarding research participation. Similarly, Kendall and colleagues (2007) found that patients participating in research felt they were given an opportunity to give back for the care either they or their loved ones received as well as being able to help improve services and support in the future. Palliative home hospice patients also expressed appreciation for being able to be involved in research that may benefit others (Dobratz, 2003). Ross and Combleet (2003) found that a palliative patient's most frequent response to being asked why they participated in research, was a general desire to help others. Research to date in the palliative care setting including this study suggests that patients are interested in participating in research (White et al., Kendall et al., Dobratz, and Ross & Combleet).

The current guidelines for palliative care are based to a limited extent on research with dying patients and their families (Heyland et al., 2005). Simultaneously, many treatments used in palliative care have little evidence of effectiveness despite the growing need for evidence-based

practice to guide any branch of medicine and nursing (White & Hardy, 2010). Thus research in this understudied population is necessary in order to build an evidence base that will aid in ensuring quality end of life care for an ever growing population. However, researching a population that is either dying or caring for the dying is fraught with challenges and questions about appropriateness. Nonetheless, a common theme presented in the study findings was one of altruism.

5.6 Rural

Issues of driving distances to access health care services were described by study participants. This finding is supported in the literature by Hughes et al. (2004) who completed a broad review of rural palliative care literature. They found that geographical distance for rural patients necessitated long commutes to access specialist care and treatment. The participants in this study showed a tolerance of this driving, adding that urban driving for specialist care and treatment is laden with difficulty and stress for some research participants.

Duggleby and colleagues (2010) found that lack of services and poor communication with health care professionals as issues for their study participants in a study of the transition experience of rural older palliative care patients and the families. Goodridge, Hutchinson, Wilson and Ross (2011) found in their study of participants living in a rural area with advanced chronic respiratory illness, that distance was a barrier to accessing health care. However, positive relationships with primary health care providers was a common theme within their study findings.

The comments made regarding the palliative care personnel and services received by all study participants were positive. Other literature suggests that palliative care services in some rural areas are limited (Kelly et al., 2004). The reasons participants did not describe this issue is unknown. It could be that research on palliative care services in rural areas has not always focused on the perceptions of the rural palliative care patients and caregivers. Robinson et al. (2009) state that the most significant gap in the literature is the perspective of palliative patients and their families regarding their experiences within the rural and remote setting. This study aided in addressing this particular aspect of palliative care.

5.7 Limitations

There were several limitations that affected this study generally falling into the categories of sample characteristics, challenges of researching the palliative population, and study design. The sample was drawn from rural areas of two health regions in the western province of Saskatchewan, Canada and rural areas excluding the cities and surrounding area of three cities in the western province of Alberta. The Saskatoon Health Region in Saskatchewan has a solely dedicated rural palliative care program while the Prince Albert Parkland Health Region in this province has a palliative care program under the auspices of Home Care. The rural areas in Alberta were serviced by palliative home care which is part of home care services and a

dedicated Pain and Symptom Control department in the Cross Cancer Institute. The recruitment in Saskatchewan provided very low numbers of potential participants with high retention once enrolled. Comparatively, in Alberta, the recruitment numbers were high with retention once enrolled lower than Saskatchewan. There was one researcher dedicated to each province to gather data from patients and their family caregivers. The quantitative data collection in Saskatchewan was more complete as a general rule than in Alberta. However, across all three sites, the findings of this pilot study were similar with regards to the qualitative data. All of the participants were English speaking and Caucasian and limited to individuals willing to participate in the study. The sample size was small limiting the generalization of the quantitative findings.

The challenges inherent in researching the palliative population of patients and their caregivers found in this study included patients feeling unwell, fatigued, busy with health care related appointments and tests, emotionally fragile and at times vulnerable. Preparation for an uncertain and unpredictable future and the emotional and physical energy that requires; as well as family caregivers protecting their loved ones remaining time and respecting their energy level necessitated proceeding with caution throughout the study. Additionally, the palliative patient population and their family caregivers is not conducive to being tested by large randomized controlled studies and often the study design may need to reflect this and make adjustments accordingly. Given the small sample size of this pilot study, the quantitative data consisted of descriptive statistics only. However the mixed method design with collecting qualitative as well as quantitative data resulted in an increased understanding of transitions experienced by rural palliative patients and their family caregivers and has provided information on the feasibility, acceptability and ease of use of the “Changes” transition tool.

CHAPTER SIX: CONCLUSION

Health care professionals must attend to the needs of our aging population as they near the end of life. The assurance of basic end of life care, including supporting people through times of transitions, is an essential nursing function. Additionally, providing this care across all possible care settings is crucial to extending both the breadth and scope of end of life care fulfilling society's obligation to assist all dying persons. This includes the rural care setting in which palliative services are often limited leading to unmet needs among those dying in rural Canada. The philosophy of nursing is congruent with the goals of palliative care in the relief of suffering and the support of quality of life of patients and their family caregivers. Nurses have the potential to make important contributions to the development of knowledge in the field of palliative care as shown in this small study. This knowledge will guide decisions regarding practice and policy. The data gathered from this pilot study have clearly demonstrated, through the overall positive nature of the results, that the intervention tool "Changes" is easy to use, feasible, and acceptable to palliative care patients and their family caregivers in rural communities. By making the examination regarding the appropriateness, efficiency, and effectiveness of nursing interventions a priority, the best possible outcomes for patients and their families will be achieved. Research and clinical practice should move towards evidence based tools so the contribution to high quality patient care is provided. The future use of "Changes" provides a concrete way of incorporating research into practice. The use of this tool may be customized to an individual's and their family caregiver's needs taking in each of their perspectives. Implications for practice and future research follow.

6.1 Implications for Practice

Palliative care is meant to be family centered and the basic unit of care is the patient and the family caregiver. Firsthand accounts of terminally ill patients and their family caregivers provide a rarely seen or heard perspective of the dying experience. The learning gained from these individuals can assist health care providers in understanding patients and their family caregiver's preferences regarding care provision. The data obtained from this pilot study relays the importance of listening to the experiences of patients as a basis for developing guidelines for services. The results of this study will enable the "Changes" tool to be revised according to patients and family caregivers' critiques after using the binder.

Primary care plays a key role in the delivery of rural palliative care. As one patient suggested, home care nurses may be the most suited health care personnel in the chain of care to assess the need and timing of the "Changes" intervention for palliative patients and their family caregivers. Nursing staff, through their therapeutic relationship and ongoing contact with the patients and their family caregivers, are ideally situated to introduce the "Changes" binder as well as facilitate its use. Patients rely on nurses, and this tool will give us the ability to enhance our care for the patients entrusted to us. Nurses can help cope with constant adjustments induced by transitions and "Changes" will aide this effort to support people through these transitions.

Supporting people through times of transitions is an important nursing function. “Changes” can raise awareness for both patients and their caregivers about transitions they are presently experiencing or prepare them for future transitions. Transitions are a stressful time for patients and their family caregivers. Preparation or forewarning may minimize the impact of transitions by providing insight into possible future transitions. The results of this pilot study will assist nurses to implement the tool in their practice. Through “Changes,” nurses can present a tool that can inform and support palliative patients and their family caregivers as they engage in transitions and the challenges inherent in the journey toward the end of life.

Communication and provision of information is one of many elements in the care of patients with incurable progressive disease. “Changes” may serve to fill an important gap for patients and their family caregivers providing a tool that may increase communication between patients, families, and care providers as the results of this study show. The provision of information through “Changes” in one binder may increase continuity of care through a complete health record in one document for all health care professionals attending to the patient. As well, “Changes” will give patients access to information with the ability to explore it in as much or as little depth as they themselves find necessary. Implementing “Changes” into practice following the education of health care personnel regarding its use will be most effective with continuing and ongoing evaluation both formally and informally so as to improve the tool according to the needs and preferences of those using it.

6.2 Implications for Research

Further research is required to assess the prevalence and generalizability of the findings to determine the utility of this tool. A broader spectrum of geographical, cultural, and care settings in testing “Changes” is required to increase the breadth and depth of utilization of this tool. Equally important is undertaking similar research with larger sample sizes as well as individuals facing end of life with other advanced incurable diseases such as chronic renal disease and congestive heart failure. Lastly, further research to evaluate outcomes such as patient satisfaction, the affect of both hope and quality of life with the use of “Changes” and the potential of decreased health care costs could be explored with future research.

For the researcher, it is noteworthy to mention that patients and their family caregivers were capable of deciding whether to participate in interviews and to negotiate the circumstances in which they wanted this to happen. The patient’s autonomy was protected either by them or for them and if their voice being heard had a high value placed on its importance, then they or their family caregivers made that possibility a reality. As the results of this study shows, the patients in this study wanted to have a voice and found the research important to them. They wanted to be heard and their reasons were based in altruism.

6.3 Researcher Reflections

At the tender age of twelve years old, unbeknownst to me at the time, I was introduced to palliative care. My grandmother was dying of pancreatic cancer and her two daughters and five daughter-in-laws cared for her around the clock in my grandparent's home. I at the time was only involved in sitting in the living room with the men as the women nursed, cooked, and cleaned wondering what was going on in that back bedroom.

My next experience came almost ten years later to the date as a student nurse placement in a dedicated palliative care unit in a local hospital. I immediately felt that this was a place I was destined to work in, but felt that I needed some life experience before I would be a nurse worthy of caring for dying patients. So I started my nursing career, always knowing that palliative care would be involved at some point in time.

Two years later, I had the honour of caring for a man very close to my heart. He was my grandfather by marriage and he was dying. He was in the very same palliative care ward as my student placement when he died and I became his family night nurse for the last few days of his life here on earth. Those were special memories caring for him and having him hold my small hand in his large soft hand while he slept. I felt it a huge privilege to have shared those times with him, just the two of us.

Following that experience, I again had the privilege of intimately caring for someone I love, my older brother. He was dying of malignant melanoma with metastases to his liver, lungs and brain. Alongside my sister-in-law, his wife and friend and family support beyond anything I have ever seen before or felt since, we nursed him at their home to his very last breath. It was two weeks of around the clock care in a house full of God's blessings, love, and laughter even as he lay dying. If I could imagine a palliative care experience for anyone I loved so much, it would have been that one with absolutely nothing I would change.

I relay the above experiences to show that the concept of palliative care has been a thread throughout my life from a very early age. Palliative care and the process of death and dying has been something I have embraced rather than shy away from. It is an area of nursing that I knew I would one day become involved in. I had originally thought that involvement would be at the bedside. However, that involvement officially first began as a researcher.

My entire nursing career to date has been either in ICU/CCU or Emergency. This type of nursing is one that lends itself to short therapeutic relationships and often we never find out the end result of the patients we send to other wards of the hospital. Researching the palliative population has shown me that it is a population that could involve short therapeutic relationships due to shorter illness trajectories, but also longer ones in which health care professionals could become quite attached to their patients and families. Regardless of how long the relationship is between patients, their families and health care providers is, I have found through doing this research that it can be one of hope, optimism, support and genuine care for other human beings.

Life is messy and a lot of that messiness comes from transitions. Everyone, young, old, sick, well, black, white, male, female, faces transitions. While dealing with those transitions, some of the hard work has to come from within individuals, some can be shouldered by family and friends and some can come from professional services. Researching a transition tool specific to the palliative population that can help those patients that may not have adequate professional services due to their choice of living in a rural area has been very rewarding. It is a concrete tool that can help nurses in the service of their patients. At the times when they themselves are not able to see a palliative patient as often as they would like, it is a tool to continue that therapeutic relationship in the between times. Even though life can be messy, this tool can help deal with that messiness and I have been very fortunate to be involved in the research of it. I will carry fond memories of the patients and their family caregivers I personally interviewed. They were open and honest. They were at times brave and at times fragile. Sometimes they were full of hope and sometimes they felt dejected. Through it all, they were just people going through transitions like we all are.

Every time I have had an opportunity to deal with anything related to palliative care, I have felt immensely blessed. Even though I feel that I am lending my knowledge, energy and talents to situations of a palliative nature, something very meaningful to me, I always end up feeling like I have received more than I have given. This pilot study has been no exception.

6.4 Final Thoughts

Death is an intensely personal experience. The introduction of palliative care services is a deeply distressing time for patients with terminal disease and their families, but also a time when information and assistance is greatly needed from the health care system. The insight gained from the palliative patients and their family caregivers willing to share their lives during this time may improve care with the possibility of more positive contributions to quality palliative care.

The results presented are important particularly in relation to the involvement of patients very close to death. Equally as important are the results in context of the family caregivers' involvement at this same time. The evaluation of "Changes" is an important step toward improving the care of rural older palliative care patients and their family caregivers undergoing transitions by supporting them through a concrete and viable intervention.

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Appendix A

“Changes” Transition Tool



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Changes



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Introduction

This is a tool about changes. It is meant to help you prepare for possible changes or events, and to connect you with services in your community. It has suggestions and information about resources to help you. It is based on what other palliative patients, their families, and health care providers have told us.

This tool can be used as you wish by you and those close to you.

You may choose to use different sections of this tool depending on what you feel you need. There is no need to complete any of the sections. It is up to you. There is a section in this binder to store what you want to share with others.

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Thoughts & Wishes

This section consists of activities about your thoughts and wishes. Each of the activities has a brief guide to give you ideas about how you may wish to start them. It is your choice how you do the activities.

Additional pages have been added to the activities if you want to use them.

You can keep this private or share it with others. That is up to you.

What Helps Me?

Guide: Think about the things that help you and give you strength:

- Begin to write a list of things below that give you strength
 - Someone else can help you write a list
 - Or take pictures of what gives you strength



My Story!

Guide: Begin below to write or have someone help you write your story

- Your story can include changes in your life
- Pictures can also be part of this story



What You Should Know About Me!

Guide: Begin below a list of things you would like to share with your family members and close friends.

- It may be memories, what you like or dislike, etc.
- This may be in words or pictures



My Goals of Care

Guide: Write below your thoughts about the goal of the care you wish to receive if you need others to care for you

- Think about changes you may experience
- Discuss this with others



Who Speaks for Me? (When I Can't)

Guide: Choose one person or more than one person who will talk for you to family, friends and health care professionals

- Write their name below so others will know.
- Tell them what you want shared with others
- Tell them what you want them to tell the doctors and nurses and other health providers
- Let this person know when they are to speak for you
- Information on advance directives can be found by contacting your palliative care coordinator – See Other Resources on p. 26



Everyday Hope

Guide: Write below what will give you hope today

- Think of what will give you hope or help today
- Think of one big or small thing you would like to finish today. (This may be something like choosing a song you want to listen to).
- See Living with Hope DVD





Common Changes for Palliative Patients & Their Families

Other palliative patients and their families said they had changes in their lives. You may or may not have these changes.

- Environment – Home & Hospital
- Roles/Relationships – Caregivers & Family
- Daily Activities – Everyday Tasks

What are possible environmental changes?

Changes in the environment include changes in the home environment during the illness and changes of location from home to hospital and long-term care.

What types of environmental changes are there?

- Moving to a new city or town
- Changing the home environment to be suitable for your comfort
- Visitors – increased visiting friends, family, nurses, etc. affecting the household.
- Confinement to the home
- Home to hospital or professional care – moving from home to the hospital or to a professional care giving setting
- Moving in – with a family member or friend (or having someone move in with you) to provide needed care and support.

Examples from others who have experienced these changes:

"She [my wife] was an outdoor person so naturally it was a big change but she did accept it and of course her condition was making her realize that she...couldn't be outdoors."

"Her [my wife] condition was changing so rapidly...But she was able to remain at home for as long as possible...um...She probably should have been in the hospital a lot sooner than she was...but that was her decision...she could remain at home for as long as possible."

What does it mean to have physical and mental health changes?

Changes in physical and mental health can occur during the illness. This can include symptoms of the illness or side effects from medications

What types of physical and mental health changes are there?

- Pain
- Fatigue
- Nausea
- Loss of weight and/or appetite
- Feeling confused, dealing with memory trouble, or reactions to medications
- Bloating/swelling
- Incontinence/ constipation
- Seeing, speaking, hearing, thinking, mobility difficulties
- Choking
- Mood swings
- Stopping work or volunteering activities

Examples from others who have experienced these changes:

"And I think like the rapid change in her [my wife] condition, the weight loss, the jaundice, the diabetes, um, her incontinence, you know...that really....I, I think that really bothered her...."

"Oh yeah, that changes, that's definite because you don't do very much. You aren't strong enough. Nope. You aren't very strong."

What are possible changes in activities of daily living?

Changes in activities of daily living can happen. They include changes in chores, eating habits, diet, career, etc. This can include anything that affects or alters the way you are used to living.

What types of changes occur in the activities of daily living?

- Needing more help from others
- Appetite and enjoyment of food
- Career – ability to work
- Sleeping difficulties
- Hobbies, leisure activities

Examples from others who have experienced these changes:

I can't hardly peel a cucumber. I can hardly wash the dishes once in a while. My husband does it most of the time.

Um ... the things I miss most are working in the yard, I love working in the yard. Looking after a garden. Keeping my home as clean as possible. Doing all my work that I should do. I miss cooking, I love to cook. I miss it...

What are possible changes in relationships and/or roles?

Changes in roles and relationships often happened as the illness progresses and you may need more help with activities of daily living.

What types of changes occur in the relationships/roles?

- Feelings of being alone
- Changes in who does the chores and caregiving
- Relationship bonds may grow stronger (or sometimes be weakened) as a result of illness
- Loss of job – losing relationships with co-workers or jobs

Examples from others who have experienced these changes:

"I really just felt like a nurse myself...That, that was how I felt. I mean, I used to work as a nurses aide in a nursing home...and I do have some...you know, knowledge...of that kind of thing...But all of a sudden the relationship of husband/wife was gone and it was nurse and patient for me...That was our, a big change."

"Our family got a little bit closer, they cared for me more..."



Resource Section

This section contains things to help you everyday, such as a contact list and frequently asked questions (FAQ)

Your Contact List

Guide: Write contact information of people you may wish to contact during your changes. These can include community resources. For example: Family doctor, nurse practitioner, home care nurse, financial advisor, lawyer, community center, spiritual support, grocer who will deliver food, pharmacist, friends and family.

Name	Contact information

Health Region Contacts

Guide: This is a list of important contacts at your health region.

Name	Contact information
Regional Medical Director	655-5869
Manager	655-5868
Saskatoon Clinical Coordinators	
Royal University Hospital	655-1876
Saskatoon City Hospital and Long Term Care	655-8786
St. Paul's Hospital	655-5520
Home Care	655-4301
Client/Patient Access Services – (CPAS)	655-4413 655-4436
Rural:	
Clinical Coordinator – Acute, Home and Long Term (Humboldt, Cudworth, Watson and Wadena)	682-8170
Home Care:	
Humboldt, Cudworth, Watson	682-2609
Wadena	338-2517
Lanigan, Watrous, Nokomis and Strasbourg	365-1433
Wynyard	554-3011
Rosthern	232-4305
Wakaw	233-4611

Health Region Contacts

Guide: This is a list of important contacts at your health region.

Name	Contact information
National Support Programs:	
Disability Benefits – Canada Pension Plan (CPP)	(800) 277-9914
Survivor Benefits – Canada Pension Plan (CPP)	(800) 277-9914
Income Tax	(800) 959-8281
Employment Insurance – Special Benefits	(800) 206-7218
Veterans Affairs Canada (VAC)	1-866-522-2111
Provincial Programs:	
Saskatchewan Hospice Palliative Care Association	540-5490
Tertiary Palliative Care Centres – Saskatoon	655-5530
Tertiary Palliative Care Centres – Regina	766-2667
Saskatchewan Health Benefits	787-3475
Community Supports:	
The Kinsmen Foundation	1-877-777-8979
Canadian Cancer Society	1-877-977-4673
Amyotrophic Lateral Sclerosis Society of Canada	1-800-267-4257
Multiple Sclerosis Society of Canada	1-800-268-7582
Kidney Foundation of Canada Saskatchewan Branch	1-888-664-8588
Canadian Paraplegic Association (CPA)	652-9644
Hope Cancer Help Centre Inc.	955-4673

Important Dates & Notes List

Guide: Write a list of important dates and appointments that you need to attend.

- Date: _____
- Activity: _____
- Notes: _____

- Date: _____
- Activity: _____
- Notes: _____

- Date: _____
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- Notes: _____

- Date: _____
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- Notes: _____

Other Resources

Websites:

- Virtual Hospice (<http://www.virtualhospice.ca>)

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

- Canadian Hospice and Palliative Care Association (<http://www.chpca.net/>)

The Canadian Hospice Palliative Care Association (CHPCA) offers leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened. You will find a list of palliative care programs in different provinces and resources.

- Caregiver Network (<http://www.caregiver.ca>)

The goal of the Caregiver Network is to be a national single information source to make life as a caregiver easier. You will find information and resources for caregiving and chat rooms to talk with other caregivers

- Canadian Cancer Society (<http://www.cancer.ca>)

The Canadian Cancer Society is a national, community based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. On their website you will find information regarding cancer and programs and services. They have a toll free number that you can use to talk with an expert and get specific information on your type of cancer.
(Toll free number is: 1-888-939-3333)

- Colorectal Cancer Association of Canada (<http://www.colorectal-cancer.ca/>)

The Colorectal Cancer Association of Canada (CCAC) is dedicated to increasing awareness of colorectal cancer, supporting patients, and advocating for population-based screening and timely access to effective treatments. Here you will find facts, risk factors and symptoms, treatment options, latest research, and support groups.

Other Resources

- Alzheimer Society (<http://www.alzheimer.ca>)

The Alzheimer Society of Canada identifies, develops and facilitates national priorities that enable its members to effectively alleviate the personal and social consequences of Alzheimer's and related diseases, promotes research and leads the search for a cure. On this website you will find facts, causes, myths, statistics, support groups and treatment options.

- Heart and Stroke Foundation (<http://www.heartandstroke.ca>)

The Heart and Stroke Foundation, a volunteer-based health charity, leads in eliminating heart disease and stroke and reducing their impact through the advancement of research and its application, the promotion of healthy living, and advocacy. On this website you will find health information about heart disease, stroke and healthy living, as well as multicultural resources.

- Lung Cancer Canada (<http://www.lungcancercanada.ca/>)

Lung Cancer Canada is the only charity whose sole mission is to raise awareness, provide patient focused information and offer peer support to everyone touched by lung cancer. On this website you will find a resource information center where you will find answers to your questions about lung cancer.

- Lung Association (<http://www.lung.ca>)

The Lung Association works at the national, provincial and community levels to improve and promote lung health. They focus on chronic lung disease like asthma and COPD, infectious diseases like TB, flu, and pneumonia, and breathing disorders like sleep apnea. They provide reliable and trusted information to both citizens and governments, and advocate for improvements when lung disease patients are getting inadequate care.

- Shoppers Drug Mart Medication Library
(<http://www.shoppersdrugmart.ca/english/healthwatch/advice/medlibrary/index.html>)

The Healthwatch Medication Library lists thousands of prescription and non-prescription medications. On this website you will find current, up-to-date information on the common uses of a medication, how a medication should be used, possible side effects, and more.

Other Resources

- Living with Hope DVD (enclosed)
- Books:
 - A Care Givers Guide: A Handbook about End-of-Life Care by Canadian Hospice Palliative Care Association (www.chpca.net)
 - A Guide for Supporting Caregiving Families: Nourishing Strengths and Open Hearts (www.familycaregiverssupport.org)
 - Companioning the Dying: A Soulful Guide for Caregivers. Greg Yoder. (2006). Ft. Collins, Colorado: Companion Press
- Pamphlets:
 - Journey's End: A Guide to Understanding the Final Stages of the Dying Process. Deborah Sigrist, BSN, RN. (2006). Hospice of Rochester Lifetime Care, 3111 Winton Rd. South, Rochester New York 14623-2988
 - Using Narcotics Safely. Caring Connections – National Hospice and Palliative Care Program. www.caringinfo.org
 - Artificial Nutrition (Food) and Hydration (Fluids) at the End of Life. Caring Connections – National Hospice and Palliative Care Program. www.caringinfo.org
 - Managing Your Pain. Caring Connections – National Hospice and Palliative Care Program. www.caringinfo.org
 - Anticipatory Grief: Information for Patients and Families. Saskatoon Health Region
 - CPAS: Client/Patient Access Services. Saskatoon Health Region
 - Nutrition and Hydration in Palliative Care. Saskatoon Health Region
 - Advanced Health Care Directives (Living Wills). Saskatoon Health Region
 - Health Care Directives. Public Legal Education Association Of Saskatchewan

Frequently Asked Questions

We have compiled a list of questions that others with life-limiting illness and their families frequently ask. For any questions contact whoever locally knows you best or contact your palliative care provider. It is important that you continuously ask questions and seek the information you need. Information may help you make decisions as you experience different changes.

Questions you may have:

1. What is palliative care?

Hospice palliative care is whole-person health care that aims to relieve suffering and improve the quality of living and dying. The services offered in palliative care programs differ depending upon where you are.

2. What services does palliative care provide? Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

3. If a service I require is not available, how do I access this service?

Call your local palliative care provider.

4. How do I find information about disease and the symptoms I should expect?

Contact your local palliative care provider about getting information and ask first for their suggestions to how you can get information. There are some internet references that we have listed them on the resources page for you.

5. Is there a list of contact names and numbers of people who may be of help to me? See list of contact names and numbers in the tool on page 19-20.

6. Are there books or internet resources available that would be of help to me?

See list of resources in the tool on page 27-29.

7. If I have any questions about my treatment plan who can I call?

You should call your family doctor if you have questions about treatment. Your doctor will be able to tell you what is best or who to consult.

Frequently Asked Questions

8. If I need to talk to a doctor or any other health care professional, what should I do? If reaching your doctor is difficult, call your palliative home care nurse for assistance.

9. How do I find information on medications?

You should consult locally with the pharmacist first. Pharmacies give information packages on the medication-. A good website for information on medications can be found within the other resources on page 28.

10. How do I obtain copies of tests or procedures I have had?

You have the right to ask for your records and test results. Before each test ask the person doing the test or procedures for a copy. If you forget, your oncologist or family doctor will have a copy.

11. What appointments or tests should I expect?

The primary goal of appointments and tests is to make sure you are comfortable. Tests are ordered in response to a new symptom you may have, or a change in your condition. Sometimes it is to monitor or prevent a problem. Its natural to wonder what is coming around the corner and care will be changing now. When tests are ordered it is important to ask: “Do I have a new problem?” “What are my health care goals and will that test help me meet those goals?” Contact your local palliative care provider for more information.

12. Is counselling available?

Your local home care nurse will be able to help you with this information. If it is not available to you through home care then you may be able to pay for it privately if it is available in your community. Call your local palliative care provider.

13. Are there support groups available?

Your home care nurse can help you with this question, and there will be information through your health region. Call your local palliative care provider.

Frequently Asked Questions

Questions Family/Friends may have:

1. Is there someone to help care for my family member at home, or do I have to do it all alone? Your palliative home care nurse can help you with this question. Usually there is someone on the healthcare team available to help, but asking friends and family is a good idea too.
2. If I do not know how to do something for my family member, is there anyone available to teach me and show me? Your palliative home care nurse is available to teach and show you how to care for your family member. There are resources for caregivers listed in the resource section.
3. What do I do if I cannot control my family members' pain or any other symptoms? Call your palliative home care nurse as soon as possible. Do not wait for symptoms to become severe.
4. Why does my family member have no appetite and not like the food he/she once used to? Often people with serious illness have no appetite for many different reasons. For example the disease and the medications change what we like or don't like. Contact your palliative care provider to get more information specific to your family member.
5. Is there someone to help me communicate with my family member through this process? Communication can be difficult at times. The most important thing is to keep trying. Contact your palliative care provider for more help.
6. Who do I contact if I need support for myself as I care for my family member? There may be many sources of personal and professional support available in your circle of family and friends and in your local community. Contact your palliative care provider to discuss your needs and concerns.



Travelling Health Record

The purpose of this record is to have important documents in a place that you can grab quickly and take with you if you need to see a doctor or go to the hospital. The following are suggestions that you may wish to include:

- a short summary of your medical history
- an updated list of your medications
- a copy of your most recent test results
- a record of your current symptoms and conditions or get someone to help you with this (This can be in the attached forms if you wish)
- a copy of your Advance Directive (Living Will) and a list of who also has a copy
- a list of doctors, nurse practitioners, home care nurses and other healthcare or community professionals who are caring for you.

Symptom Tracking Record

Guide: This is a record of your symptoms and how the medications and other treatments are working. Sometimes people find that they like to keep track of everything; others find that tracking symptoms and medications make the most sense when there are problems. You decide what is best for you. You'll note that we ask you to rate how bad the symptom is and how much distress it is causing for you. The rating scale is a suggestion – you may find one that works better for you.

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Record

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Record

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Record

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Record

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Record

Name:

Date:

A symptom (use one sheet for each symptom):

Intensity (how bad it is)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

Distress (how much it is bothering you)

0 1 2 3 4 5 6 7 8 9 10

none

worst possible

What

Helps: _____

What Doesn't

Help: _____

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Symptom Tracking Table

Directions: note your symptom intensity distress when you take medications or do something else to lessen it and 1 to 2 hours later

Date	Time	Intensity	Distress	Medicine & Dose Taken	What Else Did You Do or Try?	Effectiveness & Other Effects	Other

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>

Medication Record

Name:

Birth Date:

Doctors Name:

Pharmacy:

Allergies (include reaction):

Prescribed Medicines/ Over the Counter Medicines

<i>Name</i>	<i>Dose</i>	<i>Daily Schedule</i>	<i>Reason for medication</i>	<i>Start date</i>	<i>End date</i>



Consent Form Palliative Patient

You are invited to participate in a research project entitled **Pilot Testing of a Transition Tool for Rural Palliative Patients and Their Family Caregivers**. Please read this form carefully, and feel free to ask questions you might have.

Researchers: Lori J. Cooper, College of Nursing, University of Saskatchewan.
Telephone: 306-221-5785.

Wendy Duggleby, College of Nursing University of Alberta (supervisor)
Telephone: 780-492-8660

Lorraine Holtslander, College of Nursing University of Saskatchewan
(supervisor)
Telephone: 306-966-8402

Purpose: The purpose of this study is to evaluate the “Changes” transition tool for ease of implementation, feasibility, and acceptability for older palliative care patients and their family caregivers in rural communities. We want to know how useful the “Changes” transition tool is for you and a significant other.

Procedures: This study involves you and a significant other. We will be asking both of you similar questions and there is a separate consent form for your significant other. If you agree to participate, we will first ask you to identify a person who is helping you. Then one of the researchers (a Registered Nurse) will meet with you and your significant other at a time that is convenient for both of you.

At the first visit, she will ask questions about your age, medical history etc. to describe as a group who participated in the study. She will give you a binder called “Changes” that includes activities and information for both you and your significant other. She will explain how to use this binder. We would like you to help us understand if and or how it helps improve your situation during this time in your life. How much you look at the binder, or spend on the activities will be up to you. You can use the binder separately or with your significant other. We estimate that you may spend about one to two hours reading and working on the binder.

During the second visit, one of the researchers will ask you questions about your experience in the last week and the use of the “Changes” binder. She will ask you what activities in the binder that you worked on and how much time you spent on each activity. She will ask you to fill out a form about the usefulness of the binder and to answer questions about the research study. A portion of each of these visits will be audio-taped. If you and your significant other agree, at the

end of the second visit, some of the activities you have worked on will be photocopied and then returned to you. You can decide if you agree to this at the second visit.

One of the researchers will meet with you and your significant other twice one week apart for no more than an hour for a total time of approximately 2 hours. With your time during the week reading or working on the activities, you may spend in total another 2 hours. A total of 4 hours over a week is required of you for this study.

Potential Benefits: Taking part in this study may benefit you. Using the “Changes” binder may help you to cope with your experience better. We hope that the information you provide will assist in future improvements in the care of palliative care patients.

Potential Risks: There are no known risks to you if you participate in this study, except for your time. Talking about your experiences can be emotional at times and great care will be taken to minimize any distress talking about your life may cause. You will be referred to the Palliative Care Coordinator if you wish.

Storage of Data: Your name will not be identified on the interview tapes and there will be no identifying information on any forms. All data will be stored in a locked drawer at the College of Nursing, University of Saskatchewan for 5 years. Only the research team and their assistant will be able to look at the information. At the end of 5 years the research team will destroy the data if they wish.

Confidentiality: The forms you will complete will not have your name on them. The tape-recorded part of the visits will also not identify you. Your name will not appear on any report. All information from this study will be reported in a group format for conferences and publications so no one can identify you. Only the researchers will have access to confidential information needed to contact you such as your phone number.

Right to Withdraw: Your participation is voluntary. You do not have to answer any questions you don’t want to. You can stop being in the study any time you want. If you get tired, don’t feel well or become upset, you can take a break at any time. The research assistant is an experienced Registered Nurse and can help you if you need assistance. If you wish the research assistant will help you call your physician or the palliative care coordinator. You may withdraw from the research project for any reason, at any time, without penalty of any sort. It will not affect the care you receive. Just let any one of the researchers know.

Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on September 17, 2009 and re-approved on February 23, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call collect.

Consent to Participate: I have read and understood the description provided above: I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above and understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)



Consent Form Family Caregiver

You are invited to participate in a research project entitled **Pilot Testing of a Transition Tool for Rural Palliative Patients and Their Family Caregivers**. Please read this form carefully, and feel free to ask questions you might have.

Researchers: Lori J. Cooper, College of Nursing, University of Saskatchewan.
Telephone: 306-221-5785.

Wendy Duggleby, College of Nursing University of Alberta (supervisor)
Telephone: 780-492-8660

Lorraine Holtslander, College of Nursing University of Saskatchewan
(supervisor)
Telephone: 306-966-8402

Purpose: The purpose of this study is to evaluate the “Changes” transition tool for ease of implementation, feasibility, and acceptability for older palliative care patients and their family caregivers in rural communities. We want to know how useful the “Changes” transition tool is for you and the person you care for.

Procedures: This study involves you and the person you care for. We will be asking both of you similar questions and there is a separate consent form for the person you are caring for. If you agree to participate, one of the researchers (a Registered Nurse) will meet with you and the person you care for at a time that is convenient for both of you.

At the first visit, she will ask questions about your age, medical history and how much time you spend as a caregiver to describe as a group who participated in the study. She will give you a binder called “Changes” that includes activities and information for both you and the person you care for. She will explain how to use this binder. We would like you to help us understand if and or how it helps you in your situation. How much you look at the binder, or spend on the activities will be up to you. You can use the binder separately or with the person you care for. We estimate that you may spend about one to two hours reading or working on the binder.

During the second visit, the researcher will ask you questions about your experience in the last week and the use of the “Changes” binder. She will ask you what activities in the binder that you worked on and how much time you spent on each activity. She will then ask you to fill out a form about the usefulness of the binder and to answer questions about the research study. A portion of each of these visits will be audio-taped. If you and the person you care for agree, at the end of the second visit, some of the activities you have worked on will be photocopied and then returned to you. You can decide if you agree to this at the second visit.

One of the researchers will meet with the you and the person you care for twice, one week apart for no more than an hour for a total time of approximately 2 hours. With your time during the week reading or working on the activities, you may spend in total another 2 hours. A total of 4 hours over a week is required of you for this study.

Potential Benefits: Taking part in this study may benefit you as a caregiver of someone who is receiving palliative care services. Using the “Changes” binder may help you to cope with your experience better. We hope that the information you provide will assist in future improvements in the care of palliative care patients.

Potential Risks: There are no known risks to you if you participate in this study, except for your time. Talking about your experiences as a caregiver can be emotional at times and great care will be taken to minimize any distress talking about your life may cause. You will be referred to the Palliative Care Coordinator if you wish.

Storage of Data: Your name will not be identified on the interview tapes and there will be no identifying information on any forms. All data will be stored in a locked drawer at the College of Nursing, University of Saskatchewan for 5 years. Only the research team and their assistant will be able to look at the information. At the end of 5 years the research team will destroy the data if they wish.

Confidentiality: The forms you will complete will not have your name on them. The tape-recorded part of the visits will also not identify you. Your name will not appear on any report. All information from this study will be reported in a group format for conferences and publications so no one can identify you. Only the researchers will have access to confidential information needed to contact you such as your phone number.

Right to Withdraw: Your participation is voluntary. You do not have to answer any questions you don’t want to. You can stop being in the study any time you want. If you get tired, don’t feel well or become upset, you can take a break at any time. The research assistant is an experienced Registered Nurse and can help you if you need assistance. If you wish the research assistant will help you call your physician or the palliative care coordinator. You may withdraw from the research project for any reason, at any time, without penalty of any sort. Just let any one of the researchers know.

Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on September 17, 2009 and re-approved on February 23, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call collect.

Consent to Participate: I have read and understood the description provided above: I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above and understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

(Name of Participant)

____/____/____
(Date)

(Signature of Participant)

(Signature of Researcher)

Appendix D
Patient Demographic Form

Study ID _____

Date: ____/____/____

A. Age _____

B. Gender: [1] female [2] male

C. Marital Status: [1] Married [4] Widowed

[2] Single/never married [5] Partnered

[3] Divorced [6] Separated

D. Ethnicity: [1] Caucasian [2] African American

[3] Asian/Pacific Islander [4] Eskimo/Native American

[5] Mixed (please specify): _____

[6] Other (please specify): _____

E. Residency: [1] Acreage [2] Town [3] Farm

F. Occupation: _____

G. Education: Years of Education; _____

H. Religious Preference: _____

I. Self-reported health status: What would you say your health is right now?

[1] Poor [2] Fair [3] Good [4] Very Good [5] Excellent

J. Primary Diagnosis: _____ Date of primary diagnosis: _____

K. Date Admitted to Palliative care: ____/____/____

L. Other Diseases:

M. Medications currently using:

N. Current Health Services Being Used _____

O. Comments

Appendix E

Family Caregiver Demographic Form

Study ID _____

Date: ____/____/____

A. Age _____

B. Gender: [1] female [2] male

C. Marital Status: [1] Married [4] Widowed

[2] Single/never married [5] Partnered

[3] Divorced [6] Separated

D. Ethnicity: [1] Caucasian [2] African American

[3] Asian/Pacific Islander [4] Eskimo/Native American

[5] Mixed (please specify): _____

[6] Other (please specify): _____

E. Residency: [1] Acreage [2] Town [3] Farm

F. Occupation: _____

G. Education: Years of education: _____

H. Income: [1] Less than 30,000 [2] 30,000-39,999 [3] 40,000-49,999

[4] 50,000-59,999 [5] 60,000 or >

I. Religious Preference: _____

J. Self-reported health status: What would you say your health is right now:

[1] Poor [2] Fair [3] Good [4] Very Good [5] Excellent

K. Medical Health History: _____

L. Current Health Care Services Being Used: _____

M. Relation to Patient: _____

N. Time spent caring for patient: Number of days/week____ Number of hours/Day____
Number of weeks/month_____

O. Length of time care giving since palliative diagnosis: _____

P. Comments

Appendix F

Standardized Instructions for the Use of “Changes”

For each dyad of patient and family caregiver, the following instructions will be given in the format listed below:

1. The researcher will read the initial Introduction to the “Changes” binder, having the patient and family caregiver follow along.

Introduction

This is a tool about changes. It is meant to help you prepare for possible changes or events, and to connect you with services in your community. It has suggestions and information about resources to help you. It is based on what other palliative patients, their families, and health care providers have told us.

This tool can be used as you wish by you and those close to you.

You may choose to use different sections of this tool depending on what you feel you need. There is no need to complete any of the sections. It is up to you. There is a section in this binder to store what you want to share with others.

We hope that this tool will be of help to you.

The researcher will then ask the patient or family caregiver if they have any questions or need any further explanation.

2. The researcher will then read the introduction to the first section of the “Changes” binder entitled Thoughts and Wishes, having the patient and family caregiver follow along.

Thoughts & Wishes

This section consists of activities about your thoughts and wishes. Each of the activities has a brief guide to give you ideas about how you may wish to start them. It is your choice how you do the activities.

Additional pages have been added to the activities if you want to use them.

You can keep this private or share it with others. That is up to you.

The researcher will then ask the patient and family caregiver if they have any questions or need any further explanation.

3. The researcher will then read the introduction to the second section of the “Changes” binder entitled Common Changes for Palliative Patients and Their Families having the patient and family caregiver follow along.

Common Changes for Palliative Patients & Their Families

Other palliative patients and their families said they had changes in their lives. You may or may not have these changes.

- Environment – Home & Hospital
- Roles/Relationships – Caregivers & Family
- Daily Activities – Everyday Tasks
- Physical and Mental Health – Illness Effects

The researcher will then ask the patient and family caregiver if they have any questions or need any further explanation.

4. The researcher will then read the introduction to the third section of the Changes binder entitled Resource Section and have the patient and family caregiver follow along.

Resource Section

This section contains things to help you everyday, such as a contact list and frequently asked questions (FAQ)

The researcher will then ask the patient and family caregiver if they have any questions or need any further information.

5. The researcher will then read the introduction to the last section entitled Travelling Health Record having the patient and family caregiver follow along.

Travelling Health Record

The purpose of this record is to have important documents in a place that you can grab quickly and take with you if you need to see a doctor or go to the hospital. The following are suggestions that you may wish to include:

- a short summary of your medical history
- an updated list of your medications
- a copy of your most recent test results
- a record of your current symptoms and conditions or get someone to help you with this (This can be in the attached forms if you wish)
- a copy of your Advance Directive (Living Will) and a list of who also has a copy
- a list of doctors, nurse practitioners, home care nurses and other healthcare or community professionals who are caring for you

The researcher will then ask the patient and family caregiver if they have any questions or need any further explanation.

Appendix G

Checklist of Activities and Time Spent on Each

Section	Activity	Who: 1=Patient 2=Caregiver 3=Together	Approximate Time Spent
Section 1: Thoughts and Wishes	What Helps Me		
	My Story		
	You Should Know		
	My Goals of Care		
	Who Speaks for Me (When I Can't)		
	Everyday Hope		
Section 2: Common Changes For Palliative Patients & Their Families	Environmental Changes		
	Physical Changes & Symptoms		
	Changes in Daily Living Activities		
	Changes in Relationships/Roles		
Section 3: Resources	Your Community Resources		
	Other Resources		
	Frequently Asked Questions		
Section 4: Travelling Health Record	Symptom Tracking Record		
	Symptom Tracking Table		
	Medication Record		

Appendix H

Visit 2- Interview Guide for Palliative Patients and Family Caregivers

- a) Tell me about any changes you may have experienced this week.

Prompt: are there any other changes you are dealing with?

- b) What do you think about the binder? Has it been helpful?

- c) Do you have any questions you would like to ask me about the binder or any comments you would like to make to me regarding the binder?

Appendix I

“Changes” Transition Tool Evaluation Questionnaire for Patients and Family Caregivers

On a scale from one to five, with 1 being 'FULLY DISAGREE' and 5 being 'FULLY AGREE', please evaluate the Transition Tool answering the following questions:

1. Ease of understanding

(a) Were the directions clear for you for each activity you wanted to do?

1 2 3 4 5

If 3 or less, probe for reasons:

(b) Were you sure of what you were expected to do with each of the activities you wanted to do?

1 2 3 4 5

If 3 or less, probe for reasons:

2. Ease of implementation

(a) Did you have the energy to complete all of the activities that you wanted to do?

1 2 3 4 5

If 3 or less, probe for reasons:

(b) Were you able to complete all of the activities you wanted to do?

1 2 3 4 5

If 3 or less, probe for reasons:

(c) Did you have time to carry out the activities you chose to do?

1 2 3 4 5

If 3 or less, probe for reasons:

3. Effectiveness

(a) Do you feel working with the “Changes” binder increased your ability to deal with transitions?

1 2 3 4 5

If 3 or less, probe for reasons:

(b) Would you do it again?

1 2 3 4 5

If 3 or less, probe for reasons:

(c) Would you recommend this to someone else?

1 2 3 4 5

If 3 or less, probe for reasons:

Do you have any additional comments or is there anything you would like to tell me about that I have not asked?

Appendix J

Evaluation Interview Questions for both Patients and Family Caregivers

A. Study Participation

What was it like to be part of this study experience?

Was there anything that helped you to participate?

Was there anything that hindered your participation?

B. Tool

What did you like best about the “Changes” activities?

What did you like least?

Did working on the activities help with your awareness of your transitions?

Did working on the activities help you connect with others?

Did working on the activities help you redefine what is now your normal?

Did working on the activities change your hope or quality of life?

(prompt) Increase or decrease?

(prompt) Why did you think it changed/didn't change your hope or quality of life?

C. Do you have any suggestions?

Appendix K

Data Collection Plan for “Changes” Transition Tool – Original Plan

Initial Visit

Obtain informed written consent (patient and caregiver).

Complete demographic forms and HHI for patient and caregiver, MQOL for patient and QOLTI-F for caregiver.

Present the binder and explain tool with standardized instructions.

Schedule second visit.



Second Visit (approximately one week later)

Discuss any transitions experienced and progress with binder; answer any questions (audio-taped).

Complete HHI, MQOL, and QOLTI-F.

Obtain checklist of activities worked on and time spent on each.

Schedule third visit.



Third Visit (approximately one week later)

Discuss any transitions experienced and progress with binder; answer any questions (audio-taped).

Complete HHI, MQOL, QOLTI-F.

Obtain checklist of activities worked on and time spent on each.

Schedule final visit.



Final Visit (approximately one week later)

Discuss any transitions experienced and progress with binder; answer any questions (audio-taped).

Complete HHI, MQOL, QOLTI-F, Transition tool questionnaire and evaluation interview (audio-taped).

Obtain checklist of activities worked on and time spent on each.

Photocopy Thoughts and Wishes section of “Changes” binder progress completed to date.

Thank patients and family caregivers

Hand in information to principal investigator.

Appendix L

University of Saskatchewan Behavioural Research Ethics Board Certificate of Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval Study Amendment

PRINCIPAL INVESTIGATOR
Wendy D. Duggleby

DEPARTMENT
Nursing

Beh #
07-68

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
University of Saskatchewan

SUB-INVESTIGATOR(S)
Lorraine Holtslander

SPONSORING AGENCIES
CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR)

TITLE
Project 10 System Navigation Tool

APPROVAL OF
Phase III:
Revised consent form
Revised ethics application
Addition of Lori Cooper as student researcher
Addition of Lorraine Holtslander as co-supervisor

APPROVED ON
17-Sep-2009

CURRENT EXPIRY DATE
18-Mar-2010

Full Board Meeting ☐

Date of Full Board Meeting:

Delegated Review ☒

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

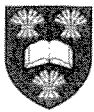
ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8



Certificate of Re-Approval

PRINCIPAL INVESTIGATOR

DEPARTMENT

Beh #

Wendy D. Duggleby

Nursing

07-68

INSTITUTION (S) WHERE RESEARCH WILL BE CARRIED OUT

University of Saskatchewan

Saskatoon SK

SUB-INVESTIGATOR(S)

Lorraine Holtslander

STUDENT RESEARCHER(S)

Lori Cooper

SPONSORING AGENCIES

CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR)

TITLE:

Project 10 System Navigation Tool

RE-APPROVED ON

EXPIRY DATE

17-Jan-2011

22-Feb-2012

Full Board Meeting



Delegated Review



CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

University of Saskatchewan

Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office

University of Saskatchewan

Box 5000 RPO University, 1607 - 110 Gymnasium Place

Saskatoon, SK S7N 4J8

Phone: (306) 966-2975 Fax: (306) 966-2069

Certificate of Re-Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Re-Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	Beh #
Wendy D. Duggleby	Nursing	07-68
INSTITUTION (S) WHERE RESEARCH WILL BE CARRIED OUT		
University of Saskatchewan Saskatoon SK		
SUB-INVESTIGATOR(S)		
Lorraine Holtslander		
STUDENT RESEARCHER(S)		
Lori Cooper		
SPONSORING AGENCIES		
CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR)		
TITLE		
Project 10 System Navigation Tool		
RE-APPROVED ON	EXPIRY DATE	
17-Jan-2011	22-Feb-2012	
Full Board Meeting <input type="checkbox"/>		
Delegated Review <input checked="" type="checkbox"/>		

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1607 – 110 Gymnasium Place
Saskatoon, SK S7N 4J8
Phone: (306) 966-2975 Fax: (306) 966-2069

Appendix M
Saskatoon Health Region Operational Approval



UNIVERSITY OF
SASKATCHEWAN

Associate Vice-President Research – Health
(University of Saskatchewan)
Vice-President Research and Innovation
(Saskatoon Health Region)
Room B527 Health Sciences Building
University of Saskatchewan
107 Wiggins Road
Saskatoon, SK S7N 5E5
Phone: (306) 966-8745

DATE: October 1, 2009

TO: Dr. Wendy Duggleby
College of Nursing
University of Saskatchewan

FROM: Martha E. (Beth) Horsburgh
Associate Vice-President Research – Health (University of Saskatchewan)/
Vice-President Research & Innovation (Saskatoon Health Region)

RE: **RESEARCH PROJECT ETHICS COMMITTEE (EC)#:** B2007-68
PROJECT NAME: Project 10 system navigation tool phase 3: pilot testing of a
transition tool for rural palliative patients and their family caregivers
PROTOCOL #: NA

Saskatoon Health Region is pleased to provide you with operational approval of the above-mentioned research project.

Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 655-1442 or email shawna.weeks@saskatoonhealthregion.ca

Yours truly,

Martha E. (Beth) Horsburgh
Associate Vice-President Research – Health (University of Saskatchewan)/
Vice-President Research & Innovation (Saskatoon Health Region)

cc: Meredith Wild, Manager, Palliative Care Services, SHR

Catalyzing Health Research and Innovation Together

Appendix N

Prince Albert Parkland Health Region Ethics Approval



Lori Cooper, BSN, RN
U. of Saskatchewan
College of Nursing, Masters Student
306-221-5785

April 12, 2010

Dear Lori Cooper,

This letter is to inform you that the Ethics Committee has met and has accepted your application to administer your study here in the health region. The committee expressed no concerns regarding your study and appreciates all of the information you have provided us. The decision was formalized on April 1, 2010.

We ask that you continue to keep the committee informed of any changes and the progress of your study on the use of a transition tool for rural palliative patients and their family caregivers (*Project 10 System Navigation Tool Phase 3*). If you need anything further please feel free to contact me: aknifton@paphr.sk.ca, (306) 765-6026.

Please be aware that while the Ethics committee is giving approval, administrative approval for participation needs to be obtained at the site by the participants. The committee has expressed an interest in the results of your study. Fulfilling this request is voluntary, and we would keep any information you provide to us confidential and secure. Any additional effort to provide the committee with your final results is appreciated.

Thank you.

Amy Knifton
Coordinator of the Prince Albert Parkland Regional Ethics Committee

PAPHR Ethics Committee, Victoria Hospital
1200-24th St. W
Prince Albert, SK S6V 5T4
Phone: (306) 765-6026 – aknifton@paphr.sk.ca

Appendix O

Alberta Cancer Research Ethics Committee Approval



30 June 2010

Dr. Wendy Duggleby
Professor and Nursing Research Chair Aging and Quality of Life
Faculty of Nursing
University of Alberta
5-125/127 Clinical Sciences Building

Dear Dr. Duggleby:

RE: **25422: Project 10 System Navigation Tool**

Thank you for your response to my correspondence dated 31 May 2010. I am pleased to grant approval to your participation in the above noted study on behalf of the Alberta Cancer Research Ethics Committee (ACREC). The following documents have been reviewed and approved as of 30 June 2010:

- Research of Minimal Risk Application (received 28 April 2010)
- Letter of support from Dr. Sharon Watanabe dated 22 April 2010
- Recruitment Script
- McGill Quality of Life Questionnaire
- Quality of Life During Serious Illness – Family Carers
- Herth Hope index
- Patient Demographic Form
- Caregiver Demographic Form
- Day 7, 14, and 21 Interview Guide for Palliative Patients and their Caregivers
- Checklist for Activities Data Collection Form
- Day 21 Changed Tool Evaluation Questionnaire
- Evaluation Interview Questions for both Patients and Family Caregivers
- Standardized Instructions for the Use of the Changes Tool
- Figure 1: Data Collection Plan
- Patient Consent Form dated 26 April 2010
- Caregiver Consent Form dated 26 April 2010

Please note that this approval is based on the following conditions:

- a copy of the informed consent form must be given to each research subject and consent obtained prior to enrollment on the study;
- if there are any other changes to the protocol or consent form during the year, or if any serious adverse events to the treatment are found, a letter describing the changes/reactions must be forwarded to the ACREC together with an updated consent form;

Alberta Cancer Research Ethics Committee 1J2 WCM, University of Alberta Hospital, 8440-112 Street, Edmonton AB T6G 2B7
Tel: (780) 407-3652/ (780) 407-1600 Email: Research.Ethics@albertahealthservices.ca

1. The membership of this Research Ethics Committee complies with the membership requirements for Research Ethics Boards defined in Part C Division 5 of the *Food and Drug Regulations*;
2. This Research Ethics Committee carries out its functions in a manner consistent with Good Clinical Practices; and
3. This Research Ethics Committee has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site(s). This approval and the views of this Research Ethics Committee have been documented in writing.

Edmonton • University of Alberta Hospital • Research

1J2 WCM, 8440-112 Street Edmonton, Alberta, Canada T6G 2B7

www.albertahealthservices.ca

Appendix P

Herth Hope Index

Visit # _____ Code # _____

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	StronglyDisagree	Disagree	Agree	StronglyAgree
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

McGILL QUALITY OF LIFE QUESTIONNAIRE

STUDY IDENTIFICATION #: _____ **DATE:** _____

Instructions

*The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.
Please circle the number between 0 and 10 which is most true for you.
There are no right or wrong answers.
Completely honest answers will be most helpful.*

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

**IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW
YOU HAVE BEEN FEELING *JUST IN THE PAST TWO (2) DAYS.***

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial -
over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Please continue on the next page...

PART B: Physical Symptoms or Physical Problems

- (1) For the questions in Part "B", please list the **PHYSICAL SYMPTOMS OR PROBLEMS** which have been the biggest problem for you over the past two (2) days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary).
- (2) Circle the number which best shows how big a problem each one has been for you **OVER THE PAST TWO (2) DAYS**.
- (3) If, over the past two (2) days, you had **NO** physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days,
one troublesome symptom has been: _____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

2. Over the past two (2) days,
another troublesome symptom has been: _____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

3. Over the past two (2) days,
a third troublesome symptom has been: _____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

Please continue on the next page...

4. Over the past two (2) days I have felt:

physically 0 1 2 3 4 5 6 7 8 9 10 physically
terrible well

PART C Please choose the number which best describes your feelings and thoughts
OVER THE PAST TWO (2) DAYS.

5. Over the past two (2) days, I have been depressed:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

6. Over the past two (2) days, I have been nervous or worried:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

7. Over the past two (2) days, how much of the time did you feel sad?

never 0 1 2 3 4 5 6 7 8 9 10 always

8. Over the past two (2) days, when I thought of the future, I was:

not afraid 0 1 2 3 4 5 6 7 8 9 10 terrified

9. Over the past two (2) days, my life has been:

utterly 0 1 2 3 4 5 6 7 8 9 10 very
meaningless purposeful
and without and
purpose meaningful

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

made no 0 1 2 3 4 5 6 7 8 9 10 progressed to
progress complete
whatsoever fulfillment

Please continue on the next page...

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:

completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile
---------------------------------	---	---	---	---	---	---	---	---	---	---	----	----------------------------

12. Over the past two (2) days, I have felt that I have:

no control over my life	0	1	2	3	4	5	6	7	8	9	10	complete control over my life
--	---	---	---	---	---	---	---	---	---	---	----	--

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree	0	1	2	3	4	5	6	7	8	9	10	completely agree
--------------------------------	---	---	---	---	---	---	---	---	---	---	----	-----------------------------

14. To me, the past two (2) days were:

a burden	0	1	2	3	4	5	6	7	8	9	10	a gift
-----------------	---	---	---	---	---	---	---	---	---	---	----	---------------

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place	0	1	2	3	4	5	6	7	8	9	10	caring and responsive to my needs
--	---	---	---	---	---	---	---	---	---	---	----	--

16. Over the past two (2) days, I have felt supported:

not at all	0	1	2	3	4	5	6	7	8	9	10	completely
-------------------	---	---	---	---	---	---	---	---	---	---	----	-------------------

Please continue on the next page...

Appendix R

QOLLI – F ©

QUALITY OF LIFE DURING SERIOUS ILLNESS – FAMILY CARERS

STUDY IDENTIFICATION #: _____

DATE: _____
Day/Month/Year

PLEASE READ THESE INSTRUCTIONS BEFORE ANSWERING

*There are no right or wrong answers. Honest answers will be most helpful.
This questionnaire includes a series of statements that we would like you to respond to
by choosing a number from 0 to 10.*

*These numbers extend from one extreme answer (for example, “not at all”)
to its opposite (for example, “completely”).*

Please choose or circle the number between 0 and 10 that best represents how you feel.

*Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best
situation is at the 10 end of the scale.*

When the best situation is at the 0 end, the text will look like this.

*We are interested in learning about your OVERALL quality of life, so please consider any issues
that affect you, even if they are not related to your caregiving role.*

A blank line in a sentence refers to the person you are caring for.

For confidentiality, please do not write their name on the line.

- A. Considering all parts of my life - physical, emotional, social, spiritual, and financial -
over the past two days (48 hours) my quality of life has been:

very poor 0 1 2 3 4 5 6 7 8 9 10 excellent

1. Over the past two days (48 hours) I was satisfied with the place _____ was staying
(home, hospital, other):

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

2. Over the past two days (48 hours) I had the privacy I wanted:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

3. Over the past two days (48 hours) the condition of ___was distressing to me:

not often 0 1 2 3 4 5 6 7 8 9 10 always

4. Over the past two days (48 hours) the amount of control I had over my life was:

not a problem 0 1 2 3 4 5 6 7 8 9 10 a huge problem

5. Over the past two days (48 hours) I had time to take care of myself:

never 0 1 2 3 4 5 6 7 8 9 10 always

6. Over the past two days (48 hours) I was able to think clearly:

not often 0 1 2 3 4 5 6 7 8 9 10 always

7. Over the past two days (48 hours) physically I felt:

extremely poor 0 1 2 3 4 5 6 7 8 9 10 extremely good

8. Over the past two days (48 hours) emotionally I felt:

extremely poor 0 1 2 3 4 5 6 7 8 9 10 extremely good

9. Over the past two days (48 hours) being able to provide care or company for_____ made me feel good:

rarely or never 0 1 2 3 4 5 6 7 8 9 10 always

10. Over the past two days (48 hours) I was comforted by my outlook on life, faith, or spirituality:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

11. Presently I feel that my life has meaning:

very little meaning 0 1 2 3 4 5 6 7 8 9 10 very much meaning

For questions 12 and 13, if you did not make important decisions or need health care in the past two (2) days, please answer for the last few times that you did.

12. Over the past two days (48 hours) I agreed with the way decisions were made for _____:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

13. Over the past two days (48 hours) the quality of health care we received was:

not satisfactory 0 1 2 3 4 5 6 7 8 9 10 extremely good

14. *Over the past two days (48 hours) I felt my interaction with_ was:*

very comfortable 0 1 2 3 4 5 6 7 8 9 10 stressful

15. *Over the past two days (48 hours), overall, I felt my interaction with the other people most important to me was:*

very comfortable 0 1 2 3 4 5 6 7 8 9 10 stressful

16. *Over the past two days (48 hours) my financial situation has been stressful:*

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

17. Over the past two days (48 hours), I was comfortable providing care:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

18. Over the past two days (48 hours) overall, I felt my relationships with the people most important to me made my quality of life:

much worse 0 1 2 3 4 5 6 7 8 9 10 much better

What do you most want the care team to know?

Do you want us to give this information to the team? Please circle: **Yes No**

Thank you!

©2006 SR Cohen and colleagues April 9th, 2007

Appendix S

University of Saskatchewan Behavioural Research Ethics Board Study Amendment Approval

	UNIVERSITY OF SASKATCHEWAN	Behavioural Research Ethics Board (Beh-REB)
Certificate of Approval Study Amendment		
PRINCIPAL INVESTIGATOR Wendy D. Duggleby	DEPARTMENT Nursing	Beh # 07-68
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT University of Saskatchewan		
SUB-INVESTIGATOR(S) Lorraine Holtslander		
STUDENT RESEARCHER(S) Lori Cooper		
SPONSORING AGENCIES CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR)		
TITLE Project 10 System Navigation Tool		
APPROVAL OF Revised Consent Form Family Caregivers Revised Consent Form Palliative Patient Revised Recruitment Protocol (inclusion of subjects 18 years and older) Addition of Five Hills Health Region Palliative Home Care	APPROVED ON 01-Dec-2010	CURRENT EXPIRY DATE 22-Feb-2011
Full Board Meeting <input type="checkbox"/>	Date of Full Board Meeting:	
Delegated Review <input checked="" type="checkbox"/>	Expedited Review <input type="checkbox"/>	
CERTIFICATION The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.		
ONGOING REVIEW REQUIREMENTS In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/		
John Rigby, Chair  University of Saskatchewan Behavioural Research Ethics Board		
Please send all correspondence to: Research Ethics Office University of Saskatchewan Box 5000 RPO University, 1602-110 Gymnasium Place Saskatoon SK S7N 4J8		

Appendix T

Alberta Cancer Research Ethics Committee Study Amendment Approval



8 December 2010

Dr. Wendy Duggleby
Professor and Nursing Research Chair Aging and Quality of Life
Faculty of Nursing
University of Alberta
5-125/127 Clinical Sciences Building

Dear Dr. Duggleby:

RE: 25422: Project 10 System Navigation Tool

Thank you for your letter dated 22 November 2010 together with a Recruitment Script and revised Patient and Caregiver Consent Forms, both dated 22 November 2010 in reference to the above named study.

On behalf of the Alberta Cancer Research Ethics Committee (ACREC) I acknowledge receipt of these documents and have reviewed them. Approval is granted for the Recruitment Script and revised Patient and Caregiver Consent Forms, both dated 22 November 2010. Approval is also granted for the amendments outlined in your letter (summarized below):

1. Inclusion criteria: age of participants changed to 18 years and older
2. Recruitment procedures: staff at pain and symptom control clinic will approach potential subjects based on eligibility and give a copy or mail a copy of the brochure to potential subjects (previously approved). If possible, the actual tool will be described or shown to potential subjects
3. Study procedures: data collection time reduced to one week following receipt of the "Transition Tool". Data collection will no longer include baseline, pre and post measures but will include evaluation survey and qualitative interview evaluating the tool.

If there are any other changes to the protocol or consent form during the year, or if any adverse reactions to the treatment are found, the ACREC requests that you forward a letter describing the changes/reactions, together with an updated consent form **to the Research Administration Office**.

Sincerely,

Raul Urtasun, M.D.
Interim Chair, ACREC

/jg

Alberta Cancer Research Ethics Committee 1J2 WMC, University of Alberta Hospital, 8440-112 Street, Edmonton AB T6G 2B7
Tel: (780) 407-3652/ (780) 407-1600 Email: Research.Ethics@albertahealthservices.ca

1. The membership of this Research Ethics Committee complies with the membership requirements for Research Ethics Boards defined in Part C Division 5 of the *Food and Drug Regulations*;
2. This Research Ethics Committee carries out its functions in a manner consistent with Good Clinical Practices; and
3. This Research Ethics Committee has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site(s). This approval and the views of this Research Ethics Committee have been documented in writing.

Edmonton • University of Alberta Hospital • Research

1J2 WMC, 8440-112 Street Edmonton, Alberta, Canada T6G 2B7

www.albertahealthservices.ca